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ABSTRACT

Written in response to questions from Head Start personnel, the manual contains information on how to provide encouragement and support to parents of handicapped children. Divided into sections with general background information and information pertaining to special problems, the 21 chapters cover the following topics (authors are in parentheses): a parent's view of her role in child care (Valerie Harra); the need for early childhood education (Gunnar Dybwad and Edward L. LaCrosse); the value of mainstreaming (Weslee D'Audney); dangers of labeling (D'Audney); confidentiality and legal rights (D'Audney); nutrition (D'Audney); transition to public school (D'Audney); the supportive role (D'Audney); parent involvement (San Delaney); and giving a head start to parents of children with visual impairments (Mary Anne Karstens), hearing impairments (D'Audney), orthopedic disabilities (Richard Galusha), speech and language disorders (Edwin Leach), health impairments (Paul Pearson), asthma (Thomas Fashinbauer), epilepsy (Harriet Major), mental retardation (Margie Armfield), severe emotional disturbances (Frank Menolascino), specific learning disabilities (John Hill), and multiple handicaps (LaCrosse), and to parents suspected of child abuse or neglect (D'Audney), Appended are a list of the types of handicapping conditions served by Head Start programs and samples of Head Start authorization forms. (SB)

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GIVING A HEAD START
TO
PARENTS OF THE HANDICAPPED

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University of Nebraska Medical Center
Omaha, Nebraska

Artwork by Helen Gloeb

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PREFACE

This manual was written in response to numerous requests from Nebraska Head Start personnel who wanted to provide encouragement and support to parents of children with special needs but were not sure of how to go about it.

The 1972 Amendments to the Economic Opportunity Act (P.L. 92-424) require that at least ten percent of Head Start program enrollment opportunities be made available to handicapped children.

Head Start programs have always involved children with special needs and provided assistance to their families. However, since the congressional mandate, there has been an obligation to search actively for handicapped children. This effort has resulted in a significant increase in the enrollment of children with severe physical, mental and emotional disabilities. Working with profoundly handicapped children and their families is a new experience for most of the Head Start staff.

Parts I and II contain general background information to help you "give the parents a Head Start."

Part III is meant to serve as a ready reference resource when you are called upon to work with a parent of a child with a specific problem.

No parent is ever prepared to be the parent of a handicapped child. Just as needs vary from child to child with the same handicap, so will the needs of parents. Success in "giving a Head Start" to parents depends upon helping them feel important as persons, letting them know that you care and helping them find the resources necessary for optimum development of their child.

The preschool child with a handicap tends to rely more heavily on his parents than do other children. In addition, parental attitudes are believed to be the single most important factor in the development of a child's personality and self-concept. Consequently, it is hoped that this manual will help you become more sensitive to the needs of parents and more confident in working with them. More importantly, your understanding of these needs will help parents become more effective in their role as parents.

Weslee D'Audney, M.S.

Omaha, Nebraska
February, 1976

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Barbara Anderson, Ellen Trumbull, and Dr. Paul C. Kennedy read the manuscript critically and offered helpful editorial criticisms and suggestions; Eileen Galloway, Jan Church typed the first copy and Cheryl Hein the final copy; their assistance is appreciated.

Last, but not least, thanks must go to all who generously gave of their time to co-author this book. It is indeed a product of group collaboration.

W.D'A.

CHAPTER 1

A PARENT'S VIEW: STOP WORRYING? NONSENSE!*

Valerie Harra

Parents, we're pretty terrific! We need to tell each other that periodically. At least once a day would be fine, but we'll settle for every now and then. We can't put our wares on a table like a salesman and we have no professional research papers to present. Unlike politicians, we dare not make grandiose promises about the future.

We see the results of our labors in ways that go unnoticed by most others, but are vastly significant to us--we see progress in our children. Sometimes it's a new word learned or pronounced properly, sometimes it's a ball successfully thrown and caught, or it may be the absence of a tantrum. We know that these little things have enormous significance.

We Are Pioneers

In our own way, we're all pioneers. How many of us knew anything at all about disability before we were confronted with the condition in our own child? How much have we learned since then? A great deal. Not in professional terms, perhaps. We don't have the professional's clinical training and broad factual knowledge. But we know our own children exceedingly well. Ours is an exquisite awareness of how a specific child's disability interacts with everything else he is and tries to be.

Some of us were first told of our child's difficulty by a professional. Others of us knew something was wrong and sought help. Whatever the

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circumstances, we depend on professionals to help our children. Each of us is indebted to more than one such person who has been on the scene at the right time with the right help. This much is clear. What is not so clearly established yet is the extent to which we, the parents, can be of assistance to professional workers in a cooperative effort to help our individual children.

We Orchestrate Our Children's Care

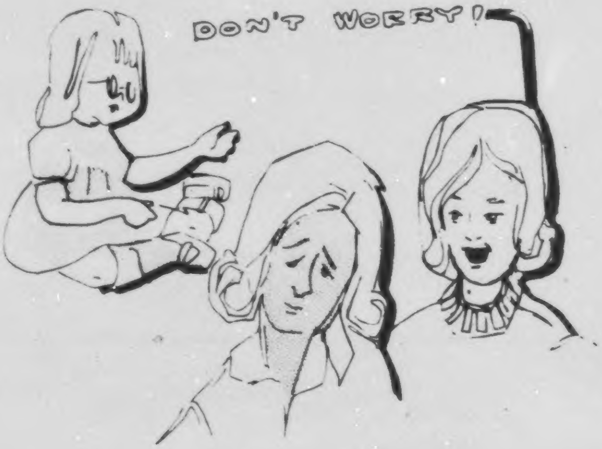
It's slowly being recognized that parents play a unique role in their children's care in several respects. First, we make the final decision about which professional to engage with our child. Second, we have a special kind of information to share with professionals about our children, for only we observe them at home in the routine of their everyday life. Third, when resources are lacking, we are the catalysts, the prime movers, in seeing that resources--educational, medical, recreational or social--are developed. Fourth, I would guess that most of us are engaged in some kind of remedial effort with our children at home, supporting their development and enriching their learning through directed efforts or weaving this "instruction" in informally during the day's activities. We also carry through prescribed medical therapies or physical therapies of one sort or another.

Finally, it is we, the parents, who have the abiding responsibility for our child throughout his dependent life, whether for a few years or well into his adulthood. Often, this ongoing support and effort by parents is what makes the difference between whether a child ultimately "makes it" as an adult, or not. The professional's help, though vital at each point, is transitory. No matter how well or poorly equipped we are to meet the ongoing demands, we bear the responsibility for orchestrating the help our child needs--and the care our child gets.

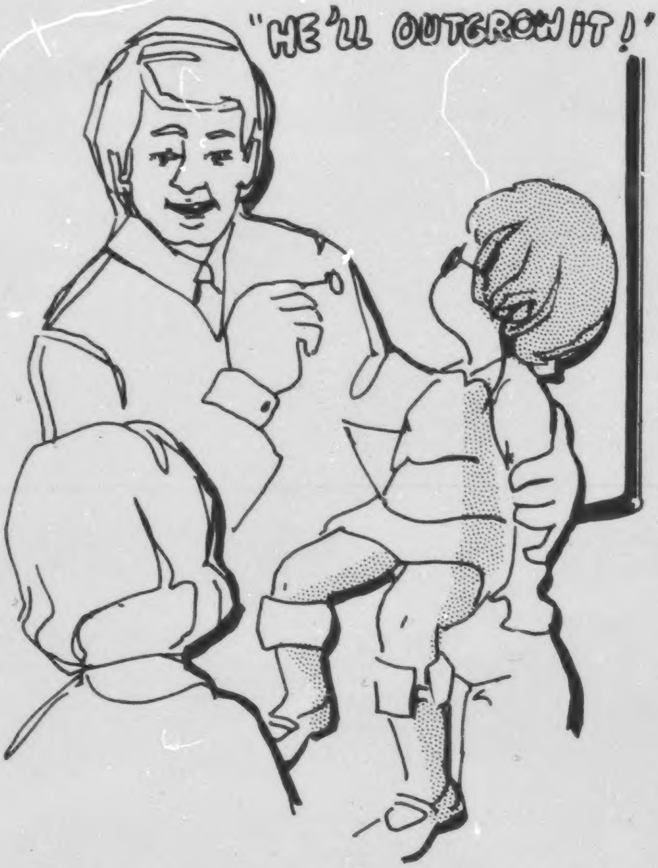
It's a difficult job. We can't afford the relief and release of total objectivity. Too much is at stake--the quality of our child's present and future life. And we can't leave the problem at the office at the end of the day. Our home *is* our "office."

Our Worry Is Appropriate

Our task is made all the more difficult when we meet the professional, relative or friend who tells us with all good intention, "Stop worrying!" or, "You're worrying too much!"--which is another way of saying, "You're over-anxious." And this makes us worry all the more, because we know we haven't succeeded in communicating the urgency of our child's situation and need. When we're in a dialogue with a professional, this communication gap can have serious consequences.



Too often we hear of parents who try to bring a troublesome physical condition in their child to the attention of a pediatrician who dismisses it, saying, "He'll outgrow it," only to be confirmed later when it may be too difficult (or too late) to correct it. How many times have we heard stories of parents trying to get help at school for a child whose performance is characterized as a "behavior problem" or "not trying hard enough"? The parents know from their observations at home how hard their child is trying; his "problem" behavior is a symptom, not a cause, of his frustration and failure. Then, upon testing, the child is discovered to have a perceptual handicap, petit mal epilepsy, or a visual or hearing disorder of some kind.

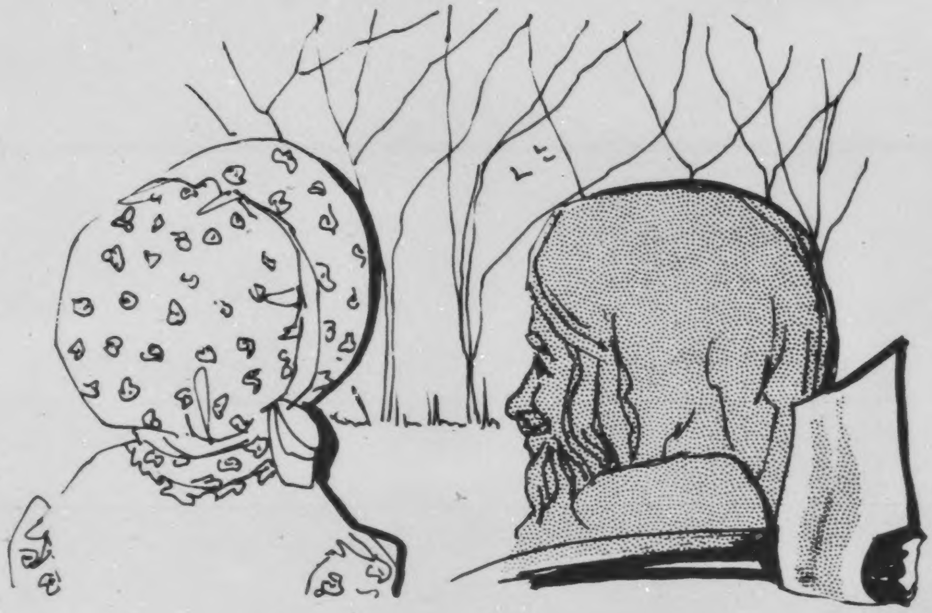

"HE'LL OUTGROW IT!"

When parents see that their child is in trouble, but that help is not forthcoming, you can bet they'll get anxious. When parents insist on bringing problems to the attention of professionals, are they "over anxious"? Or properly concerned?

Our Concern Changes as Our Children Change

When our child's difficulties are recognized and supportive help is available, that doesn't automatically dispel all anxiety. Chronic conditions don't disappear with remediation, although they may become more manageable. Each new situation, each new stage of life, presents a forest of unknowns to be dealt with. A change of school or a new teacher, an infant in the family, a new child in the neighborhood--any of these events can be a special challenge to our children. Or, the change may be internal, generated by a new stage of development. The "Terrible Two's" are the "Terrible Two's," no matter what else the child is dealing with, or what his chronological age when he arrives at that stage. Adolescence is a headholder for everyone. The difficult task of establishing a sense of identity is blurred further by a disability.

As each new situation or development presents itself, the parent is again a pioneer, trying to hack out a new path, looking for a familiar



trail. The fact that many of our children cope as well as they do is a tribute to their inner strength and resources, *and ours*. The fact that many fail, or feel that they do, is a sad commentary on the lack of ready outside support and resourceful help. We know our children can "make it" when given the opportunity to do so.

How Others View Our Concern

It is curious that others look askance at our concern and special effort in behalf of our children. When there's a news story about a child trapped down a well or requiring blood donations, total strangers will respond and offer help. These people are applauded for their concern and generosity. And so they should be. They are responding to a recognized need. However, when a parent makes a similarly dedicated effort in behalf of her own child whose needs *she* clearly recognized, she's told, "You're over-anxious. You're worrying too much." Who is more entitled to worry? A complete stranger or a parent?

Sometimes, these discouraging assessments can be completely deflating. Often, they inhibit us from persevering with our efforts. We may feel intimidated, foolish or guilty. One of the reasons we're put on the defensive is because of the social stigma attached to the terms "over-anxious," "anxious," or even "worried." Somehow, if one is visibly anxious about something, it is all too often taken as a sign that one must be "neurotic" and therefore incompetent. Who wants to be considered incompetent precisely when she is trying to enlist help for her child? *The last thing we should do is stop trying.*

What Is Anxiety?

Let's stop and take a good look at this nasty term *anxiety*. This is hard to do because anxiety is a shifty word. In clinical terms, it has to do with fear that seems "unrealistic." For instance, some people treat a sneeze as if it were pneumonia, or a momentary pain as if it were a symptom of cancer. But we can dispense with the clinical phenomenon, because what we're talking about here is entirely different--namely, proper concern with the problems which encumber our children. This is something very realistic.

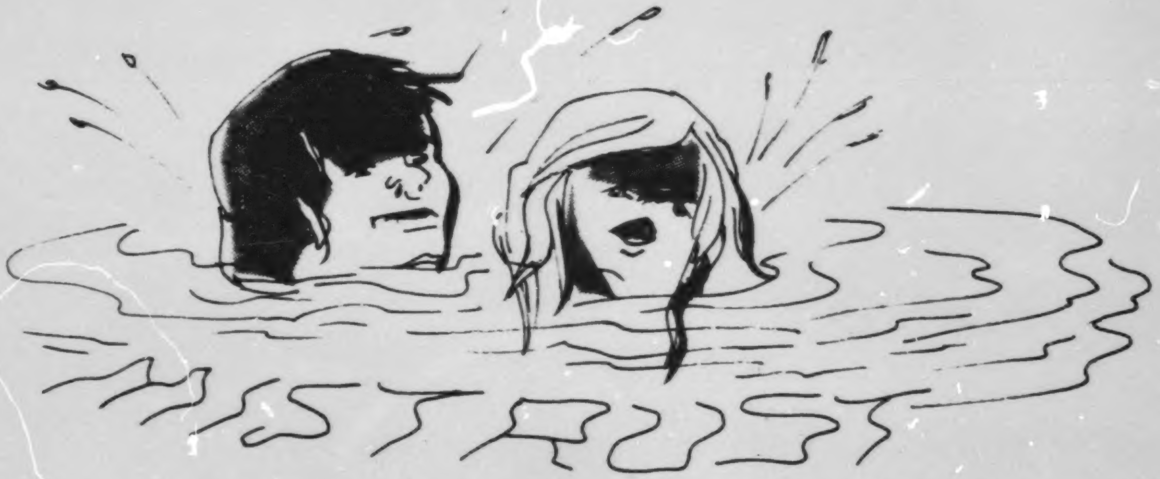
In everyday usage, anxiety means fear or apprehension. As we all know, when a child is in difficulty, whether the difficulty is considered "minimal" or severe, there is due cause for apprehension. There is no such thing as a "minimal" disability if it's a condition which interferes with a child's normal development and threatens his future. Parents have no choice. We worry about it, whether it's a heart condition or stuttering, an emotional disturbance or poor coordination, autism or a hearing impairment.

Invisible Heroism

What about the advice to "Stop worrying!"? That is about the most outlandish combination of words I can think of in this context. One might as well tell a movie audience to stop worrying about the heroine tied to the railroad tracks with a locomotive coming around a blind curve. As long as a problem remains unresolved, one for which we feel a responsibility, it's human nature to be in a state of *active concern*. And when the problem involves our own child who has special difficulties, we worry. We'll stop worrying when we know our children are secure. It's that simple. Moreover, it's a waste of energy to worry about the fact that we're worrying.

So, most of the time we respond. Our anxiety doesn't overwhelm us--although it has that potential. Instead, our anxiety makes us alert and ready to continue. It's one thing to summon energies and resources in a crisis situation and to take action--a man rescues a child from an icy lake and becomes a hero. But it also takes courage, resourcefulness and devoted determination to be an everyday hero or heroine. And this invisible heroism is what goes on in families with children with special needs. These rescue operations in the home are usually not matters of high drama, but of tedious dailiness. It may mean preparation of a special diet, every meal, every day. It may mean giving medication several times a day, every day. Or giving a patient answer to an impatient child. Or giving the same answer or showing the same process for the 800th time to an uncomprehending child. It means long waits in a doctor's office or clinic to see a physician for a few brief minutes. Or conferences with teachers, principals, athletic coaches, camp directors or therapists many times during the year. It means trying to re-establish some equilibrium in a family put off-center by the time and attention absorbed by the child with the greater needs.

This kind of effort goes on every day of every week of every year. There are no headlines or medals. But this kind of heroism is as vital to our child's well being as his being rescued from an icy lake. Because as we well know, without proper and sufficient ongoing support, our children do drown. They drown in their own mistrust of themselves and others, in



their sense of failure and frustration, or in a condition which (if allowed to) envelops and suffocates their individuality.

We get worn down by the unending demands and pressures. The very fact that these responsibilities are tedious, repetitive and undramatic, however essential, makes us bored and irritated with carrying them out. Then, on top of everything else, we start to worry that we don't love our child enough. Such worry confuses the issue. We're entitled to notice and resent the internal bruises we suffer from the anxiety that bangs around inside, and the aches from the ongoing chores. But this is distinct from the love for our child and the commitment to him which keeps us at our tasks.

We're In This Battle Together

Perhaps one of the most difficult aspects of living with a child whose problems are not easily resolved is the inevitable sense of isolation. You're aware that to the world at large, you look as if you're doing perfectly ordinary things -- going shopping, taking care of work in an office.

But your thoughts and feelings are really elsewhere -- on an invisible battlefield fighting an undeclared war that only you can see, hear and feel. In a "real" war situation, at least everyone is aware of the same dangers and appreciates the stress that each is experiencing. How do we answer the casual conversation-opener "What's new?" Not knowing how to begin to explain, we find ourselves answering "Oh, nothing much."

The fact is, we're all in the same battle together--the ongoing struggle to do the best we can for our children under difficult circumstances. The message in all this is "Trust yourself!". Because of your close bond with your children, because you have been alerted by your concern to act on their behalf, because you know them "subjectively," you do a job for your children which no one else can do. Fellow parents, you're okay!

RECOMMENDED READING

The Exceptional Parent (magazine)
P. O. Box 964
Manchester, New Hampshire 03105

One year subscription (6 issues) - $10.00

Chapter 2

EARLY CHILDHOOD EDUCATION IS ESSENTIAL TO HANDICAPPED CHILDREN*

Gunnar Dybwad and Edward L. LaCrosse

Many specialized nursery school programs are limited to children afflicted with a special handicap. Children with severe physical involvement may require a nursery school program as part of a hospital regime or other specialized treatment. This may be a necessary part of the admission criteria or simply a result of the isolationist attitude of the community towards such children.

Recently there has been less emphasis on specific disabilities and more attention given to the common problems facing handicapped children. An increasing number of nursery schools are serving children with various handicaps. The nursery school teacher may have just a few physically or mentally handicapped children in a class where the rest of the children are not handicapped. While performing a valuable service to the handicapped child, the school is enriching the range of social experiences for the non-handicapped children in a very meaningful way. Overall, an awareness is growing in the United States of the many ways the nursery school can and does serve handicapped children.

When a child is brought to the nursery school, attention is focused on his ability to function in a group situation with its constantly new

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*This chapter was adapted from an article that appeared in the *Journal of Nursery Education*, Vol. 18, January 1963. Copyright 1963, National Association for the Education of Young Children, 1834 Connecticut Avenue, N.W., Washington, D.C. 20009. It is reprinted by permission from *Young Children*.

experimental situations, created, not just by the teacher, but by the ever varying interaction of the children. In his own home, the child's inability or unwillingness to achieve a particular task may have gone unnoticed, or have been only passively noticed because demands were not placed upon him in ways that would have exposed his underlying disability.

Comparison With Other Children

A parent, seeing the child function largely by himself, may be unaware that he is avoiding certain types of activities, or certain movements. In familiar surroundings, his limited vision or hearing may go unnoticed. In the nursery group, comparison with other children or established norms of behavior may raise questions about the child's performance, resulting in referral for clinical evaluation or furnishing important clues to the clinician.

It merits underlining that *it is not suggested here that the nursery teacher should act as diagnostician or amateur clinician.* Her role is that of skilled observer. When it comes to group contact, she might well make observations that would escape a clinician whose contacts have been limited largely to an occasional one-to-one relationship. The quality of the anecdotal records kept by the teacher will have particular importance here.

Unlike an older handicapped person who has suffered an injury the very young handicapped child who has been kept at home often has had no opportunity to compare his functioning with that of others. The nursery school often provides a supportive environment in which he can become aware of his own differences.

When the handicapped child views the world in distortion, he does not know that his view is distorted. Unless the parent is particularly perceptive, this may not be observed, or if casually observed, the degree of distortion may not be fully appreciated.

In the nursery school, a planned effort is made to ask him to replicate what he sees, hears, or feels, and as he does so, his distortions become obvious in comparison with other children. This allows for observations leading to an evaluation far richer and more useful that the home observations alone.

Often a differential diagnosis and referral for correction is made because of the astute observation of a nursery school teacher. For example, a young girl attending a preschool program was referred as being mentally retarded, emotionally disturbed with organic brain damage. The teacher observed that her apparent disorganized behavior followed a definite pattern. In the classroom she constantly ran to the opposite side of the room with apparent eagerness, but then bumped into things. After a moment she rapidly repeated the process in the opposite direction.

It seemed to the teacher that the child behaved as if she could see clearly at a distance, but was confused by what was close to her. Referral to an ophthalmologist was suggested and a visual distortion was discovered. Once this was alleviated, the child's unusual behavior ceased. She could fully participate in the regular nursery school activities and moved on to elementary school where she is doing satisfactory work.

Nursery School Helps the Parents

Along with the nursery school's contribution to the professional, clinical evaluation of the handicapped child helps the parent to arrive at a more realistic assessment of the degree of the child's disability and of the ensuing handicap. Pediatricians have long recognized that their task in interpreting to a parent the severity of their child's condition and the degree of the consequent deviation from the normal patterns of physical growth and behavior is made much easier if they encourage the parent to describe the child and his performance and achievements at length. Often the parent is able to volunteer that perhaps the child is "different" or retarded or severely handicapped.

Helpful as this procedure is in many cases, infinitely more advantage will accrue if the parent can observe the child in the setting of a nursery school against the background of a group of children, particularly in a structured program. Part of the advantage, of course, rests in the fact that a mother can be an observer more easily if she is not part of the setting. With proper guidance from the teacher, the parent can gain a better understanding of her child's functional limitations and a greater appreciation of some of his assets and the potential for compensatory patterns.

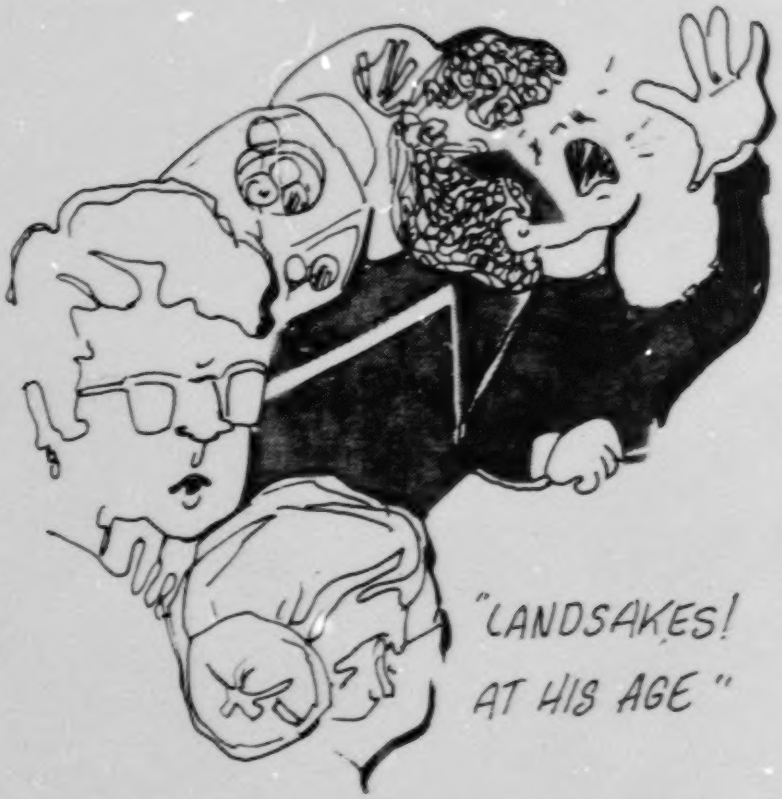
Frequently observing the child in the nursery school setting may help the parent to seek correction of the child's disability. Such a step will hardly be pursued unless the parents are actually reconciled to the existence of the disability and more specifically of the resulting handicap. Only then, will parents no longer try to shield themselves by denial.

In the specific area of the parent-child relationship, the child's behavior and often the parents' comments can provide important clues. Dr. Leo Kanner on several occasions vividly described the devastating effects on a child of a home situation where the child's disability is so much the center of attention, (what with special diet, medications, special exercises, visits to clinics) that the child feels his disability is more important than he is as a person. The nursery school may then be the only haven where the child can be himself. This is particularly the case when the presence of non-handicapped siblings impresses on the child that he is "different" because of his handicaps.

Even when gross maladjustment exists, separation for part of the day can lead the mother and the child to an appreciation of each other's role. While this is a concomitant of all nursery education, it is of special significance when the child's handicap is apt to be a disturbing factor in the parent-child relationship.

Nursery School Helps the Child

Contributions to the diagnostic process are not the only particular assets of the nursery school for handicapped children. Another advantage ties in the area of timing. We live in a society exceedingly receptive to and tolerant of very young children. The very young child of nursery school age is still allowed to be different but as he moves up the chronological age range, the demands for conformity become more and more stringent.



The handicapped child who has the advantage of a nursery school education can learn the lessons of socialization before the frustrations in his relations with his contemporaries have become acute.

In the protective yet stimulating and challenging environment of the nursery school, the child can learn to conform to the many social demands he will face eventually in his motor, social and intellectual behavior. At a time when he has not yet been subjected to the pressures of society's demands for conformity in appearance as well as in performance, he can learn in a realistic, accepting, and challenging environment to recognize the extent of his handicap and to get along with others within his own limitations.

Some of the foregoing comments have stressed certain environmental differences between the home and the nursery school. Compared with the experiences awaiting the child in elementary school and in other community settings, the nursery school experiences are of course closer to those of the home, less demanding and much better able to allow the child to explore. Little by little he gets used to the demands he will have to face later.

There is another facet to the propitious timing of the nursery school experience in the handicapped child's life: Even with a disability that does not become worse the effects may increase at a geometrical rate as the child grows older unless ameliorating, balancing, or compensatory mechanisms are brought into play early. A chain of events can all too often be observed: Because the child has a disability, his family (and later the community) tends to protect and isolate him. Fear that the child may overexert himself physically or get into situations where his sensory or intellectual limitations may engender danger leads the parent to impose excessive restrictions on the handicapped child's play activities, his moving about, or his associations with playmates. As a result, the child has less opportunity than other children have to gain experiences. Nor will he be able to utilize the experiences allowed him to the degree that a non-disabled child will. If his visual or auditory defect decreases communication with his environment, he will be deprived of important environmental stimuli usually taken for granted with the average child.

Without the helpful intervention of a nursery school experience, the spastic child may become more and more withdrawn. As his spasticity

keeps him from making social contacts on his own, he will increasingly doubt his ability to make such contacts. As a consequence, he will avoid them more and more, so that by the time he reaches elementary school, the social manifestations of his disability may outweigh the original physical problem. Herein lies an important point for the nursery school teacher who is fearful of becoming involved with physically handicapped children lest she be unable to cope with problems outside her ken. The help these children need from her lies in an area where she has particular competence.

Nursery School Helps the Home

Guided observation in the nursery school gives the parents a chance to see with their own eyes how differently the child can act once removed from the protective, unwittingly restrictive home situation. Moving on from guided observation to guided participation, parents may have a chance to work with another child who has the same disability avoiding the emotional involvement inevitably a part of working with their own child.

A nursery school providing such learning opportunities for the parents will contribute substantially to an improved home situation, particularly in the area of independence between parent and child. Frequently, matters stagnate at this point, whether due to the parents' emotional need to keep ministering to their "poor baby" or whether other duties keep them from taking the time to train the child towards gradually assuming greater self-reliance.

The nursery school can afford to let Jimmy take twenty minutes to remove his cap, his coat and his overshoes, but once he has learned to manage this within a reasonable time span, the newly gained skill can be applied at home.

"EARLY CHILDHOOD EDUCATION IS ESSENTIAL TO HANDICAPPED CHILDREN."

Chapter 3

THE VALUE OF MAINSTREAMING

Weslee D'Audney

Until the turn of the century, the options available to the parents of handicapped children were extremely limited. They could either keep the child at home or place him in an institution. Gradually, because of parental demands, society began to recognize its responsibility to provide special education for handicapped children. However, these classes were either in special schools or well separated from the so called "normal" children. The classes were neatly sub-divided into categories: the deaf, the blind, the mentally retarded, the physically handicapped, the emotionally disturbed. Though these classes were taught by specially trained teachers, they presented little or no opportunity for the children to interact with their non-handicapped peers.

During the past five or six years, a new philosophy has developed and there is a definite trend toward integrating these children, whenever possible, into regular day care, preschool, elementary and secondary classrooms rather than channeling them into isolated special programs. The new word for this is "mainstreaming," placing handicapped and non-handicapped children in a classroom for the purpose of educating them together.

Most educators agree that there will always be some children who will benefit most from a special school which is designed to remedy their specific disability. A key feature of the most recent legal decision regarding the education of the handicapped is the right of the "least restrictive alternative." This means that handicapped children should be placed where they can best be educated at the least distance from the mainstream of society. If they must be sent to a special school, or to a special education classroom within a regular school, the programs should be aimed at eventually integrating them into a regular class.

The emphasis, therefore, is placed on teaching the child to cope with his unique learning problems regardless of the type of disability.

"Mainstreaming" is still a rather new concept in education. Most of the opinions about it are based on philosophical considerations rather than hard data. High school administrators and teachers have expressed some real concerns about its practicality at that level of education because the gap widens between handicapped children and their age mates as they grow older. There may be such great discrepancies in social maturity, academic skills and future planning needs that educating them in a regular class would be a disservice to both the handicapped children and their classmates, and place added burdens on the teacher.

"Mainstreaming" has had much more acceptance at the elementary school level and most early childhood education specialists wholeheartedly endorse it.

Dr. Jenny Klein*, Director of Educational Services, and Dr. Linda Randolph, Director of Health Services, both in the Office of Child Development, have stated the reasons they feel preschool programs that integrate handicapped and non-handicapped are desirable.

- There are more similarities than differences between most handicapped children and other children.
- Integrating handicapped and non-handicapped children at an early age tends to foster tolerance and understanding among both groups.

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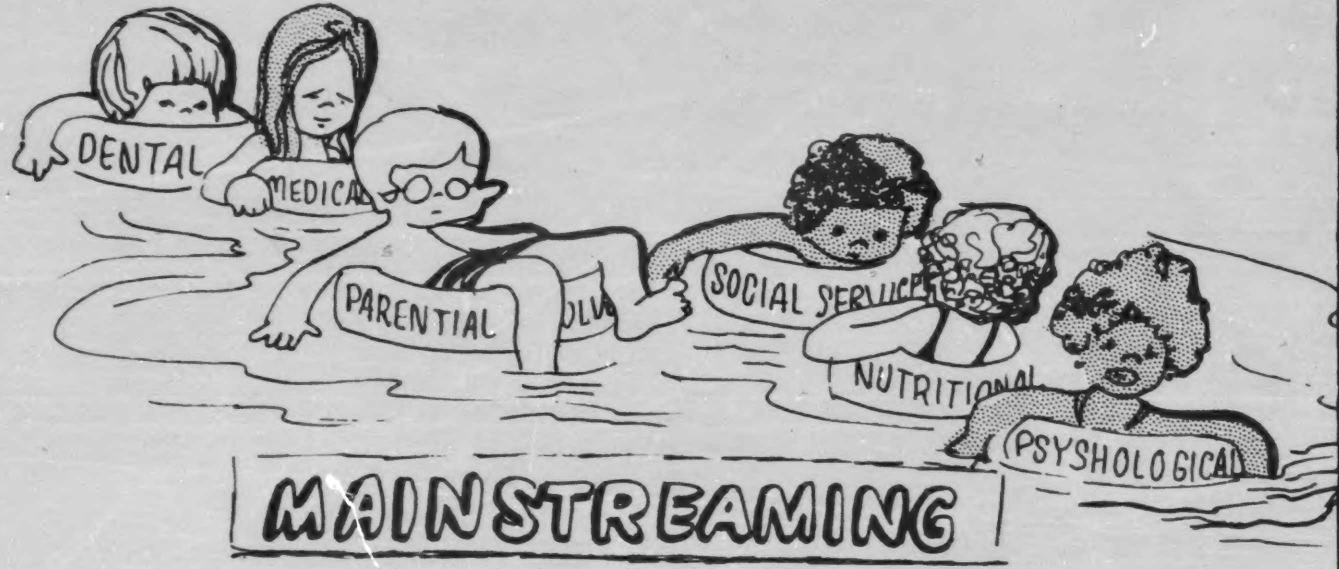
*Klein, Jenny W. and Randolph, Linda A. "Placing Handicapped Children in Head Start Programs," *Children Today*, December 1974.

- Learning and playing together can strengthen motivation, achievement and social competence in the handicapped child.
- Nearly all children can learn, although the pace and mode of their learning may differ.
- The general conditions for fostering optimal physical, emotional and intellectual development at an early age are similar for both handicapped and non-handicapped children.

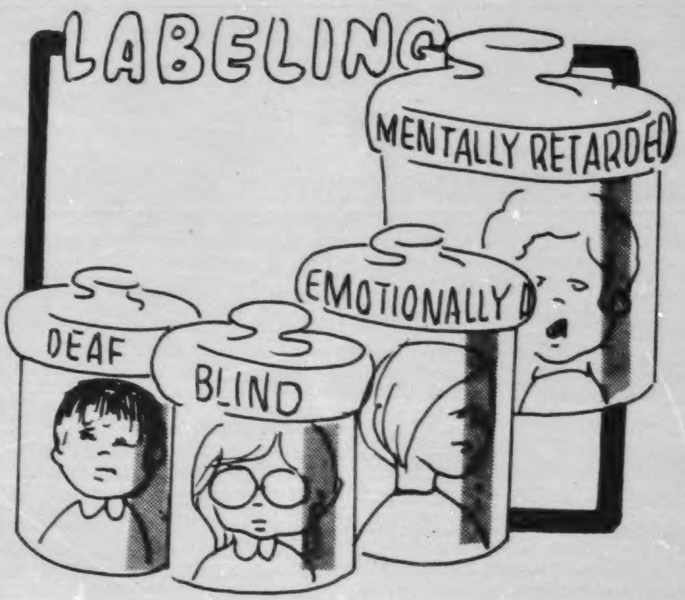

DENTAL
MEDICA
PARENTIAL
OLV
SOCIAL SERVIC
NUTRITIONAL
PSYSHOLOGICAL
MAINSTREAMING

The currents of "mainstreaming" call for full supportive services, knowledgeable teachers and individualized instruction. In Head Start these conditions can be met through a finely meshed network of activities; educational, medical, dental, psychological and nutritional and through the provision of social services and the involvement of parents.

DANGERS OF LABELING

Weslee D'Audney

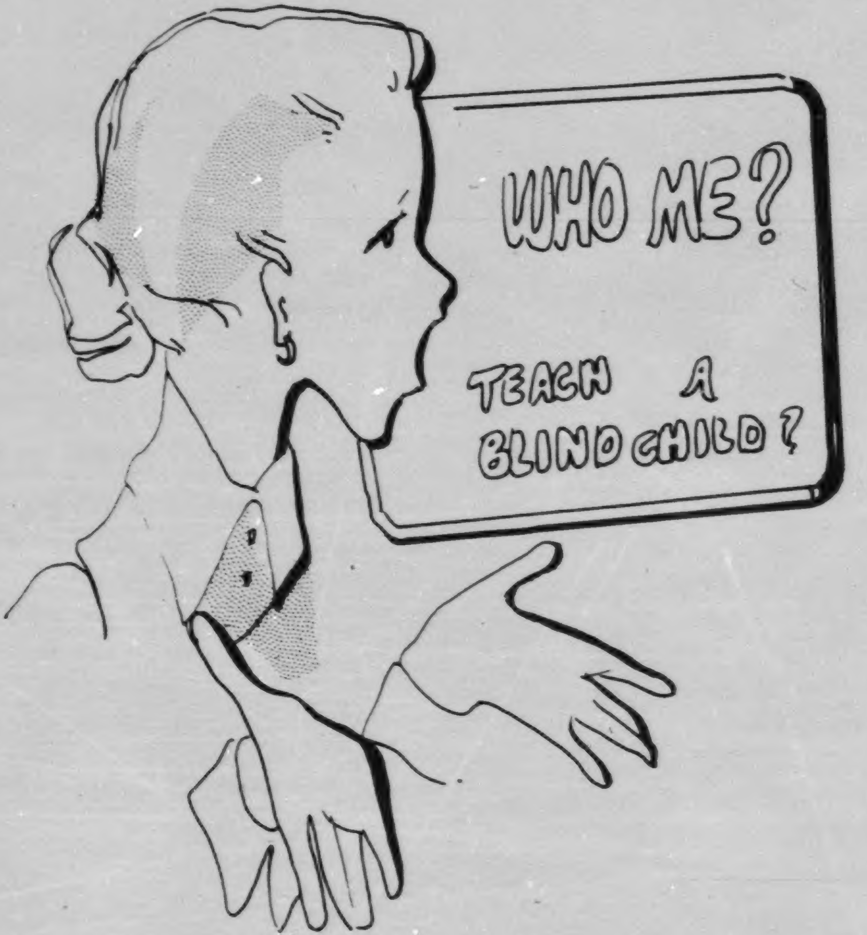
Labels, such as "mentally retarded" or "emotionally disturbed," for example, really tell very little about the condition of a child. The words tell us that the child has a handicap but not whether the disability is severe or mild or how or when the label came to be attached to the child. It certainly does not give the teacher or the parent any clues for helping the child to overcome his disability.



Recently, the practice of labeling and categorizing children by professional educators and child care workers has been strongly criticized.

The terms, while useful as a communication device for specialists and professionals, are often misunderstood by non-professionals and the parents of the children. The use of labels can produce stereotypes or mental sets that can be extremely damaging to the child. Each child has strengths as well as weaknesses and they cannot be portrayed in a single word or two. Moreover, what the child *can* do is much more important than what he can't do.

Even capable teachers have been known to "shake in their boots" when they first learn they are to have a deaf or blind child in their class.


WHO ME?
TEACH A BLIND CHILD?

Molly C. Gorelick*, noted special educator, has said, "Before we can succeed in integrating children with handicaps, we will have to overcome the

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*Gorelick, Molly C. *What's in A Label?* a paper written at California State University at Northridge.

insecurity of teachers and the attitude that only specialized experts can work with children with handicaps." She goes on to say, "Those of you who have children in your classes who are blind, deaf, retarded or with other handicaps have found that these children ride the same tricycles, climb the same jungle gyms, lick their fingers after stirring some delicious mixtures, throw sand, hug you or taunt you--in other words, they really are children."

In Head Start, the label is used anonymously for reporting purposes only. It is recommended that the professional's certification of the child's handicap remain in the custody of the Head Start Director or the Handicapped Coordinator.

Until a few years ago, many educators felt that once a child's I.Q. was determined at the age of 4 or 5, he could be slipped into the correct educational slot and that was that. Now we realize that children of the same age with the same I.Q. may have very different needs and the I.Q. score, like the label, tells very little about the functioning of the child.

There is a very real danger that the preschool child's label will follow him into regular school. The child's condition may have improved significantly during the time the child was in Head Start and the label may no longer be appropriate. The child may have fit into the integrated Head Start program without any difficulty. But if his file contains a label as handicapped, he may automatically be placed in a segregated special education class.

The child's file should contain a descriptive profile of his developmental level in social-emotional, cognitive, language, gross and fine motor abilities. An awareness of the child's sequential development in each of these areas will enable the teacher to plan an individualized program tailored to the child's specific needs. The profile will let the parents know exactly what the child can do and, used periodically, will provide evidence of the child's progress. Unlike the label and I.Q. score, the profile of abilities will provide usable information for future educational planning.

RECOMMENDED READING

Meyer Children's Rehabilitation Institute Teaching Program for Young Children. CEC Handicapped in Head Start Series, Council on Exceptional Children, 1920 Association Drive, Reston, Virginia 22091.

Learning Accomplishment Profile. Student Stores, Daniels Building, University of North Carolina, Chapel Hill, North Carolina 27514.

Portage Project Checklist. Cooperative Education Service Agency 12, 412 East Slifer Street, Portage, Wisconsin 53901.

Hobbs, Nicholas. *The Futures of Children: Categories, Labels and their Consequences.* A report of the Project on Classification of Exceptional Children. San Francisco: Jossey Bass Publishers, 1975.

Chapter 5

CONFIDENTIALITY AND LEGAL RIGHTS

Weslee D'Audney

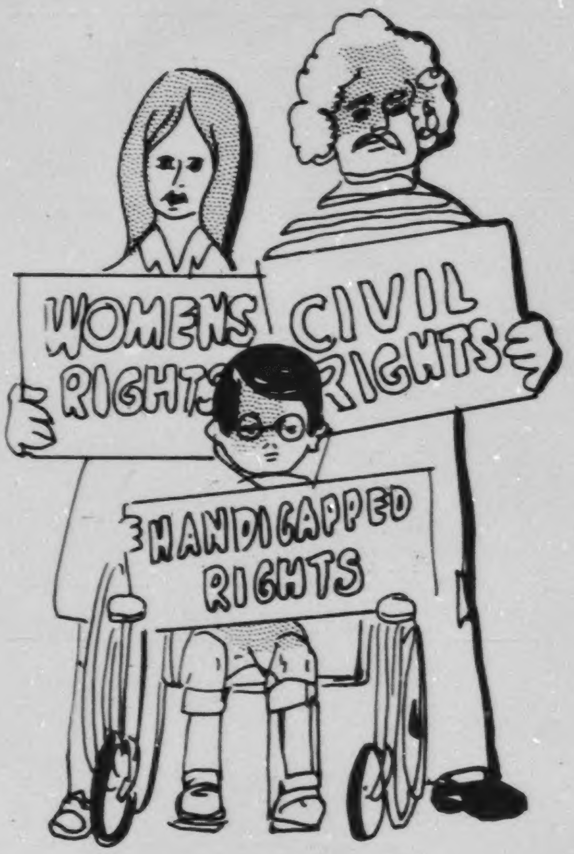
> During the past several years, there has been an unprecedented response on all levels of government to the needs of handicapped children. Landmark court decisions, extensive state legislation, congressional action and broad revisions in school board policies all reflect a new concern and a new determination that are sweeping across the country. Fundamentally, these actions are part of a profound change in our society away from an image of the handicapped as objects of charity and toward a view which sees those who are "different" as members of the human family, fully entitled to all rights of membership.
>
> The change in attitude has been long in coming. It had to be formulated in the minds and hearts of *parents* first, before it could take hold as an idea that could change the old way of doing things. Over the past two decades, that is exactly what has happened. Parents have thrown off the stigma that excluded their children and themselves from the mainstream of life. They have come forward with the certainty that *all* children and *all* adults are included in the right to share in the privileges, opportunities and risks of the real world to the fullest extent of their ability.
>
> From *Closer Look*

According to a U.S. Office of Education report early in 1974, fewer than half of the nation's six million school aged handicapped children were receiving the special education they needed and very few of the estimated one million preschool handicapped children were receiving services.

Handicapped children have been accepted in Head Start programs since its inception in 1965. It has only been since the congressional mandate in 1973, however, that there has been a vigorous outreach program to identify and recruit eligible handicapped children.

Jean Nazzaro* has reported, "Where children were designated as handicapped after they were enrolled in the Head Start program, a number of parents did not know that their children had been so identified.... This situation is potentially explosive...." The Head Start child has a right to services and his parents have a right to be a part of *all* the decisions made concerning their child. The parents have the right to be notified when specialists are called to diagnose a child's condition. They may observe the testing procedures and have every right to a clear explanation of the child's problem. Parents should also be intimately involved in the recommendations for a remedial program.

Although most states had for many years guaranteed the fundamental right of education, children with certain disabilities or behavior disorders were denied admission to schools on the theory that public education was the right of those "capable of benefitting" from the instruction offered. It was not until the 1970's that the United States Supreme Court decided that "no child is uneducable or untrainable" and "when the state undertakes to supply an education to all, that right must be made available to all, including the handicapped on equal terms."



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*Nazzaro, Jean. "Head Start for the Handicapped--What's Been Accomplished?" *Exceptional Children*. October 1974.

This decision has had far-reaching impact on special education programs across the country. It has also stimulated state and national legislation concerned with the rights of handicapped children and their parents.

In 1973, the Nebraska Legislature passed LB 403, familiarly known as the "Right to Education Bill," to guarantee the right of the handicapped child in Nebraska between the ages of 5 and 18 to a meaningful education. Most states have now passed similar mandatory education laws for the handicapped. Many of the new laws call for advisory councils of parents and specialists to serve as full partners with administrators in planning the child's education. Protection of the "due process" rights of parents and children are guaranteed by provisions for including parents in diagnostic and placement procedures and by carefully spelled-out requirements for hearings to which parents can appeal if they are not satisfied.

Right to Privacy

In 1973, Nebraska adopted a confidentiality law which said that only parents, students, legal guardians, teachers, administrators and counselors have the right to view a student's records.

The following year, Congress passed the Family Educational Rights and Privacy Act based on the Nebraska statute. Head Start personnel should be aware of the pertinent provisions. Basically, the federal law gives parents the right to inspect records and files directly related to their child, including intelligence and psychological test results, teacher evaluations, health data, comments on the child's behavior and family background. This law applies to preschools as well as other educational institutions and specifically states that federal funds may be denied if parents' rights are not respected.

The law also enables parents to challenge any information that they feel is incorrect or misleading.

It requires written parental consent before information about a child can be released to public or private agencies except to:

(1) the Department of Public Welfare in connection with financial aid;

or

(2) a school system in which the parents plan to enroll the child. In the latter case, the parents should be notified and reminded of their rights to inspect the records.

In other words, only parents and assigned Head Start staff with a legitimate educational interest can legally look at a child's records. Get a signed permission from the parents before giving out any information about the child, orally or in writing.

The release of information form should include the name of the child, the nature of the records to be released, the reason for the release, to whom the records should be released, the guardian's signature, a witness's signature and the date. (See sample release form in Appendix.)

Head Start agencies may also have to secure the parents' permission to obtain county welfare, medical and screening records.

Any information about a Head Start child and his family is considered confidential and should be used only in the best interests of the child and his family. Parents must be able to trust the discretion of the Head Start staff.

> Parents are in the forefront of the action. They are finding out what their state and national laws do and do not do and what exclusionary practices take away the right to education which the law guarantees.... They are speaking up at public hearings to defend changes in funding priorities and adoption of new programs. They are making sure that children who are "hidden" are found, that individual parents are given the opportunity to share, question or oppose diagnostic or educational decisions about their children; they are following through to insure that laws that have been ordained in the past are implemented in the present.
>
> From *Closer Look*

RECOMMENDED READING

Pamphlets

Closer Look
Box 1492
Washington D.C. 20013

Closer Look is a service to help parents of children with emotional, physical and mental handicaps find educational and related services by providing them with information. By writing to the above address parents will receive: *Practical Advice to Parents* (a booklet) and a free subscription to periodic reports from *Closer Look*.

Allen, Richard. *Legal Rights of the Disabled and Disadvantaged.* Superintendent of Documents, Washington D.C. 20402.

Ogg, Elizabeth. *Securing the Legal Rights of Retarded Persons.* Public Affairs Pamphlet #492, 381 Park Avenue South, New York, New York 10016.

Books

How to Organize an Effective Parent Group and Move Bureaucracies. Published by: Coordinating Council for Handicapped Children, 407 South Dearborn, Chicago, Illinois 60605 ($1.50).

Weintraub, Frederick J., Aberon, Allen R., and Braddock, David L. *State Law and Education of Handicapped Children: Issues and Recommendations.* Reston, Virginia: The Council for Exceptional Children. 1975.

Chapter 6

NUTRITION AND THE HANDICAPPED CHILD

Weslee D'Audney

Adequate nutrition is an important factor in the growth and development of all children, but for some handicapped children proper nutrition may be an important factor in survival.

Handicapping conditions that may require nutritional guidance and counseling include cerebral palsy, spina bifida, mental retardation, "brain injury," cardiac disease, diabetes, asthma, cleft palate and others. Special feeding practices, techniques and equipment will frequently be needed.

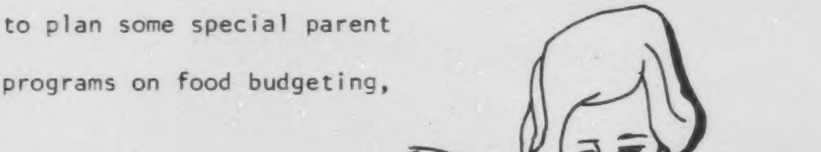
Parents should be taught the basics of nutritional management, selection of suitable goods and feeding techniques by the doctor managing the child's case. In a large medical center, where the child is evaluated by an inter-disciplinary team, the nutritionist and occupational therapist will work with the parents and the child to determine the most efficient feeding procedures for the child.

The Head Start staff can learn a great deal about the handling of a handicapped child from the parents. This is especially true of his feeding likes and dislikes, allergies, and food restrictions. They have had several years of experience at this. The type of diet recommended by the doctor may be determined by the child's condition and cultural food preferences of the family. There are several factors to be considered in food selection: the texture, the nutritive value, the calories, and the biochemical composition of the food as well as the appearance, smell and taste.

For the child who is on a modified diet because of a metabolic disease, such as diabetes or phenylketonuria, professional dietary counseling for the family is essential.

For the severely handicapped, the doctor will be concerned not only with what the child eats but how he eats. Many of the severely involved cerebral palsied children and mentally retarded children may have difficulty sucking, chewing and swallowing. Special techniques for feeding will be needed. The occupational therapist, the physical therapist and the doctor will evaluate together the need for special chairs or positions for feeding. Spill-proof cups, weighted dishes to prevent slipping, rubber coated spoons or spoons bent to a different angle may be recommended.

The Head Start nutrition coordinator should be involved in the discussions of special feeding needs. She may want to plan some special parent training programs on food budgeting,



food preparation, the importance of the atmosphere at mealtime within the home and the participation of the handicapped child in family activities--especially at mealtime. The County Home Extension Agent may also be a useful resource for the family. They are all trained in nutrition, home economics and normal child development.

RECOMMENDED READING

Finnie, Nancie R. *Handling the Young Cerebral Palsied Child at Home.* New York: E.P. Dutton, 1970. ($3.50)

U.S. Children's Bureau: *Feeding the Child with a Handicap*, Public Health Service Publication #2091, 1970. U. S. Department of Health, Education, and Welfare. ($.35)

Chapter 7

THE TRANSITION TO PUBLIC SCHOOL

Weslee D'Audney

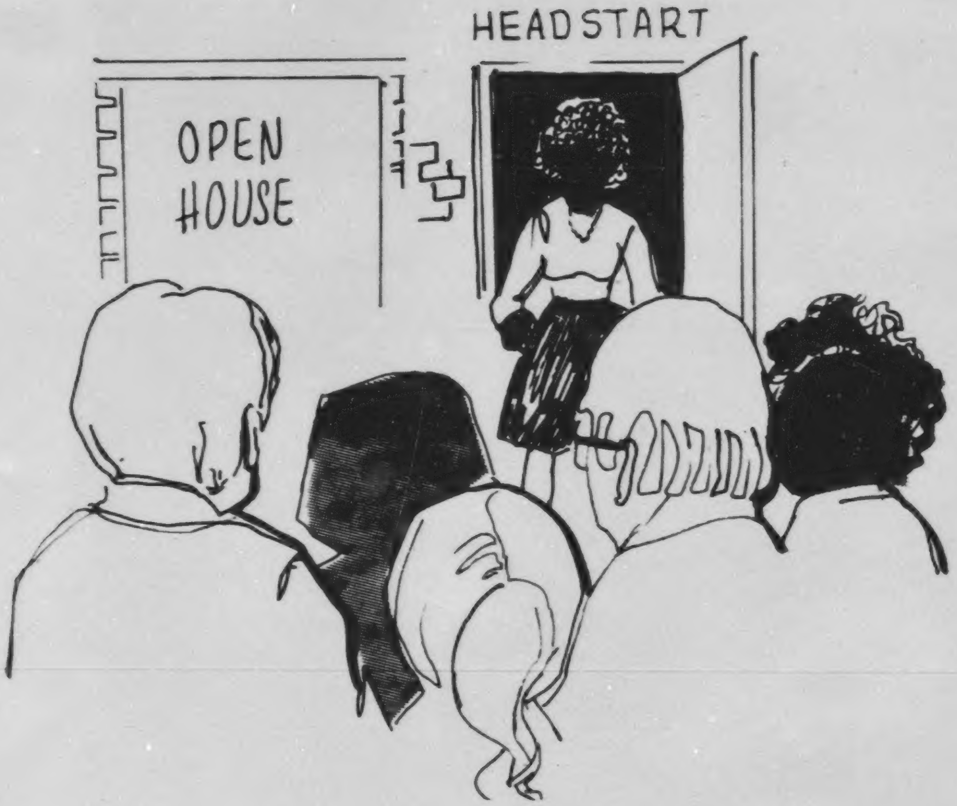
When the idea for Head Start was first conceived back in the sixties, one of the original purposes was to give disadvantaged children the background of experiences and opportunities for skill development that other children had before they entered school.

Low income and especially low income minority children often started school behind the other children in the skills necessary for academic success. Some of these children had never used a pencil or crayon, had never cut with scissors and many had a limited vocabulary. Within a year or two, these children began dropping even farther behind the rest of the class. They were "turned off" by school because of their frustrations and frequent failures. By the time second or third grade rolled around, these children were often inappropriately placed in special classes for the Educable Mentally Retarded.

Preparing children for successful entry into school is just one of the many objectives of Head Start. It is an important facet of the program for all children and of special significance for the handicapped children now being recruited and enrolled.

A Smooth Transition for All Children

Take a good look at your public relations effort. Establish a cooperative arrangement with the public schools in your area.



Have an open house for the principals, kindergarten and first grade teachers from these schools. Explain to them what the Head Start program is all about and what you are attempting to do for the children. Public school personnel need to know that Head Start is not a baby-sitting agency.

Cement relationships by asking for their help in planning your program. What are the skills they want children to know when they come to school? What methods do they prefer? If the kindergarten teacher feels very strongly that children in her class should learn upper case letters first, you can make her role easier by printing the children's names on their artwork or lockers in upper case letters. If she values the ability to wait in line or take turns, you can give special attention to developing those attributes.

Ask for permission to visit her classroom. Then you can see for yourself what she expects of the children and observe her methods. She won't thank you if she has to "unlearn" or "unteach" some of the things you've spent a lot of time and effort teaching the child to do.

Find out what the school's previous experience with Head Start children has been. The comments of the teachers may pinpoint some weakness or omission in your educational plan.

With the parents' permission, share the things you have learned about the child with his new teacher. Then the teacher will be off to a "Head Start" and so will the child.

A Smooth Transition for Handicapped Children

There are several things Head Start programs can do to make the transition for the handicapped child a little smoother.

The Head Start staff is aware of the child and his special needs for at least a year and maybe two before he is of school age. They can recommend, soon after the child is enrolled in Head Start, that the parents visit the superintendent of the school district to talk about the child's special needs. This way the school district will have ample time to either find or come up with a suitable program.

The Head Start staff can ask the parents to sign a "release of information" form so reports of consultants, developmental checklist information and classroom records containing pertinent information about the child can be shared with the school district.

At the very least, the Head Start staff can alert the school district without naming names, to the fact that they can expect a child to enroll the following year who will be presenting specific special needs.

These measures will enable the school to plan for needed special services, therapists, equipment, or to look for teachers with the needed qualifications. The child will benefit from a continuity of the individualized services he received in Head Start.

SCHOOL
"WE'VE BEEN EXPECTING YOU"

Part II

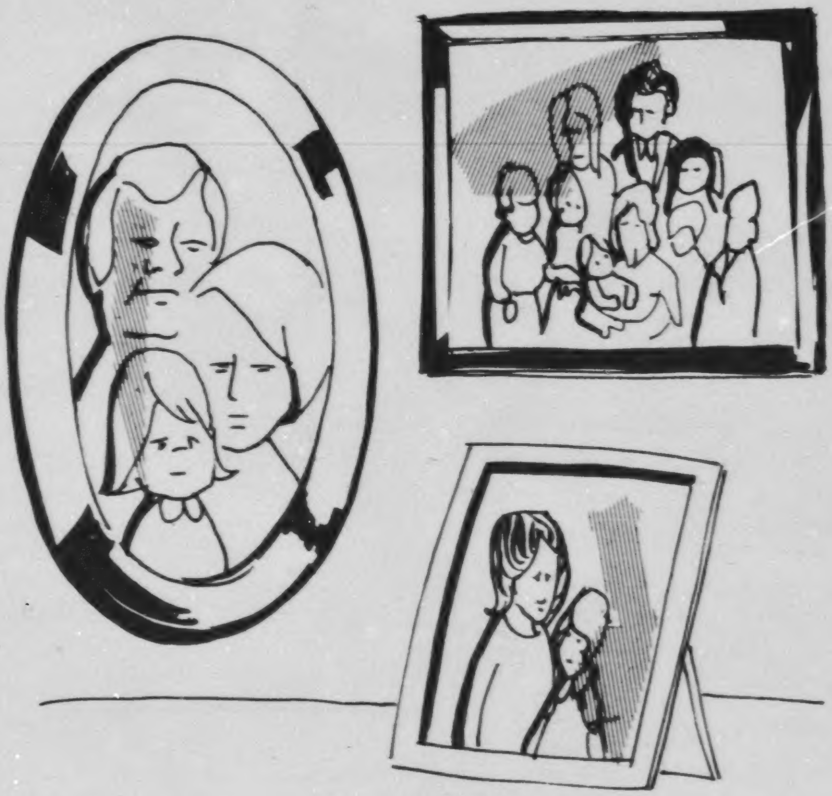
Chapter 8

THE SUPPORTIVE ROLE

Weslee D'Audney

Understanding Parents

Parents of special children are first of all people in their own right and as different as the children themselves.



They come from a variety of educational and cultural backgrounds. For some, the special child is the only child in the family; for others, one of many. Some parents receive help from a large extended family, while single parents often shoulder all the responsibility alone. Parents whose child's disability was diagnosed at birth will have a different set of concerns from those child's problems that were identified after the child was enrolled in Head Start. The parent's needs will vary according to the type and extent of the child's disability and the individual family circumstance. Therefore, this chapter must be written in general rather than specific terms, focusing on parents' shared concerns. Each disability presents some unique areas of concern and these will be discussed in Part III.

Bringing up a child with a disability calls for special energy and effort. The parents can't compare notes with their neighbors or friends or turn to grandparents for ready made solutions. There are no readily available guidelines for raising a special child.

Mrs. Max A. Murray,* parent of a mentally retarded child says, "In the early stages of our initial adjustment to life with a handicapped child:

- we need someone who will explain the disability to us in lay language.
- we need someone to help us understand our own attitudes and feelings in relation to our handicapped child.
- we need someone to give us guidance in the simple, basic processes of home training.
- we need someone who can put us in touch with the various community and state agencies that can help with constructive management of the child.
- we need guidance from someone who can help us see that this thing which has happened to us, even though it may be a *life-shaking* experience, does not of necessity have to be a *life-breaking* one."

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*Mrs. Max A. Murray. "Needs of Parents of Mentally Retarded Children." NARC

Fears of Parents

When parents first suspect their child has a problem, the seeds of fear are planted. When the child fails to master the developmental milestones on schedule or when their worst suspicions are confirmed, fears may temporarily overwhelm them. There are financial worries about the cost of getting special help or treatment, fear of what family and friends will think, fear about their own inability to cope, fear that their other children may be adversely affected, that future children will have the same problem and just plain fear of what the future will bring.

The concerns of the parents, whether founded on solid evidence or imagination, are real to them. Listen to the parents and observe the child carefully. Try to find appropriate resource help to either reassure the parents there is nothing amiss, or to treat the child and give the parents practical advice on how to cope with the situation.

The most difficult time for parents is right after they learn their child has a problem and before they know what to do about it.

Family Dynamics

Too often, the father is the "forgotten man." Make a special attempt to schedule home visits and conferences at a time when he can be present, too. He is probably as concerned as the mother and may find the situation even more difficult to accept. The continued improvement of the child's function

requires adaptations by both parents and agreement on the management of the child. Whether the parents are strict or indulgent is less important to the child's development than the fact that they are loving and consistent in their handling of the child.

There is no doubt that the presence of a handicapped child places extra strain on the family. Tensions may make tempers flare and curtail communication between husband and wife. Weak marriages may not be able to tolerate the challenge of raising a handicapped child. Other couples find their marriage strengthened by the common bond of love and concern for the child. They develop a "Together, we can handle this" attitude.

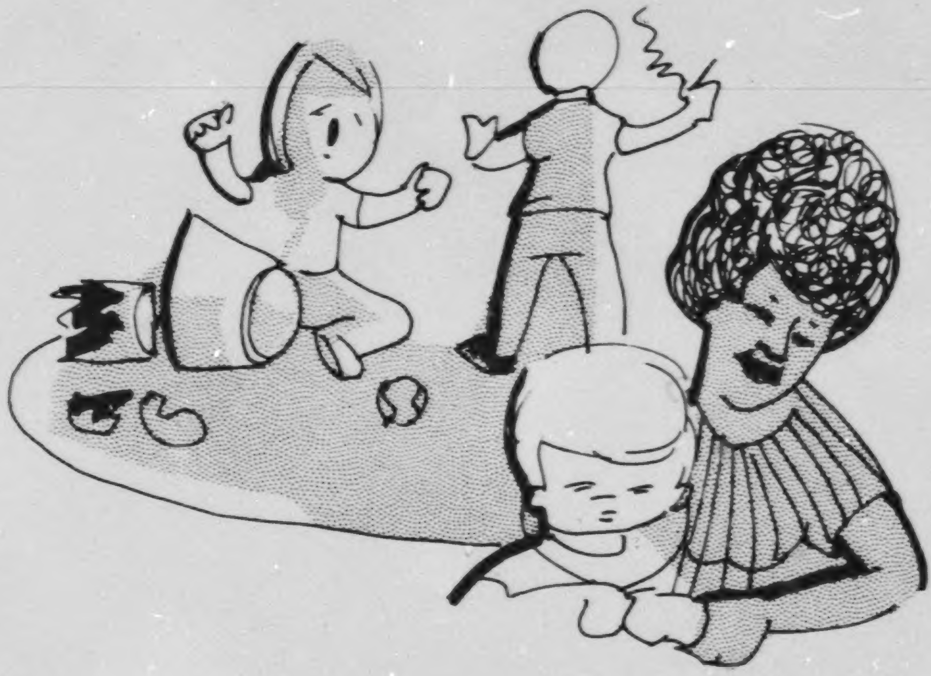
Parents of handicapped children have many roles in life beside that of being parents. They are also husbands and wives, sons and daughters, breadwinners, gardeners, musicians, etc., and this balance of interests and responsibilities must remain intact.

Parents set the stage for the way the other children in the family will view the child with a handicap. If they speak openly of the disability, the brothers and sisters will accept it as just another fact of life. Parents must be careful to give *all* their children the attention they need.

- Every child needs to feel loved.
- Every child needs to express his feelings and to feel understood.
- Every child needs to feel that he belongs and is accepted.
- Every child needs to feel secure and free from fear.
- Every child needs to feel independent.
- Every child needs a chance to discover the world.
- Every child needs to achieve and feel successful.

- Every child needs a good self-image.*

If parents spend too much time with one child, and ignore the needs of the others, those children may misbehave to get attention or become jealous of the handicapped child. Minor squabbles and disagreements between brothers and sisters are normal in any family and parents should be reassured that they don't occur just because one of the children happens to have a disability.



However, siblings have a right to get angry when the handicapped child is not disciplined for misbehavior or made to toe the line as far as respect

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Understanding the Problem Children by Lewis E. Rath and Anne B. Barrell. West Orange: Economics Press, 1963.

for their belongings is concerned. They should not be expected to become full time live-in playmates and babysitters for the handicapped child, but should be encouraged to make their own friends and be assured of some time alone with their friends when they come to visit.

How To Provide Encouragement and Support

Know Your Limitations. Professional counselors have years of training before they are qualified to serve as social workers or therapists. Your main function is to provide emotional support to the parents and to find ways to increase and enhance the interaction between them and their child.

Dr. Alice Hayden,* Director of the Model Preschool Center for Handicapped Children at the University of Washington, advises:

> Indeed there may be many things parents need to know, but let's start with what they perceive to be their needs and let them discover other ways we can work together as partners. No professional team, no matter how expert, can meet all of the child's or parents' needs at the same time.

Try to keep your discussions with parents child-centered. If the parents seem to need a marriage counselor, a mental health specialist or a doctor, refer them to the appropriate professional for help. There will be some things you just cannot do.

Be Natural and Friendly. Parents will feel better about raising their disabled children if they can talk freely about their anxieties, fears, joys and successes. You can help by putting them at ease with a friendly and relaxed attitude.

Parents of children with handicaps often become very sensitive to the reactions of others; a prolonged stare at their child in the grocery store

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*Dr. Alice Hayden, *Training Parents to Teach: First Chance for Children, Vol. 3.* Chapel Hill, North Carolina, 1974.

by a stranger or an overheard remark such as "I wonder what's wrong with him," may trigger a defensive attitude to conceal the hurt. So they will be able to sense whether your concern is genuine or whether you are faking it. You can plan an important part in building up the parents' self-image by talking *with* the parents and not *to* them. Your best chance to establish rapport is to extend the hand of friendship and lend a receptive ear in a non-judgmental, approving way.

Be Positive. Focus on the child's strengths wherever you can, and plan with the parent to find ways to use the child's strengths to overcome his limitations or weaknesses. Explain the values of early intervention and education and how activities are individualized in your program to meet each child's needs. Show the parent how the child's progress is charted and how your program taps into local and state resources for additional help for the child.

Be Perceptive. In order to provide emotional support to parents you must be perceptive of their needs as well as those of their children. Just as handicapped children can't express their needs in words, neither can most parents.

The dangers inherent in labeling children were discussed in an earlier chapter. Parents, too, are often described in terms of labels such as "rejecting, "overindulgent," "overprotective," "denying," "guilt ridden" and so on, all with negative connotations. To establish a warm, trusting relationship with a parent, avoid thinking in terms of labels and look for the cause of the parent's feelings. Could it be a reaction to disappointment, a mourning for what might have been, deep grief, fear, shock, or maybe even anger; anger that deadens the pain? Most parents of children with handicaps feel sad, not guilty--sad that this child will not be able to function like other children, sad that their child has to grow up in a world that may be non-accepting and sad because their dreams of a perfect child have been shattered. To feel sad when there is good reason is not neurotic it's a normal reaction.

There are three stages that many parents go through after learning their child has a serious disability.

The first is denial. Some parents choose to deny the child's handicap even though they know it exists because it is too painful to talk about. Others ignore the handicap in the hope that it will go away if they don't recognize it.

The second stage is intellectual acceptance. The parents may be so caught up in their own sadness that it is all they can think about. They tend to think of their child as a handicapped child first of all rather than as a child like other children but with some very special needs. Parents may become too protective at this stage and center their lives around the child or they may become so discouraged they give up doing anything for the child or themselves. Feelings of ambivalence toward the child are common during this stage.

The third stage is emotional acceptance. It is at this stage that the parents are eager to learn all they can about the child's disability and how best to help him become independent.

Not all parents go through these stages, of course, but most do require a time of adjustment which will vary in length from one parent to another before they can say, "This is the way it is. I don't like it, but I can't change it, and I must work with what exists."* Since the children

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*Quote from "Areas of Concern for the Counselor in a Diagnostic Clinic for Mentally Retarded Children," by Linn Zook and Charles Unkovic, *Mental Retardation*, June, 1968.

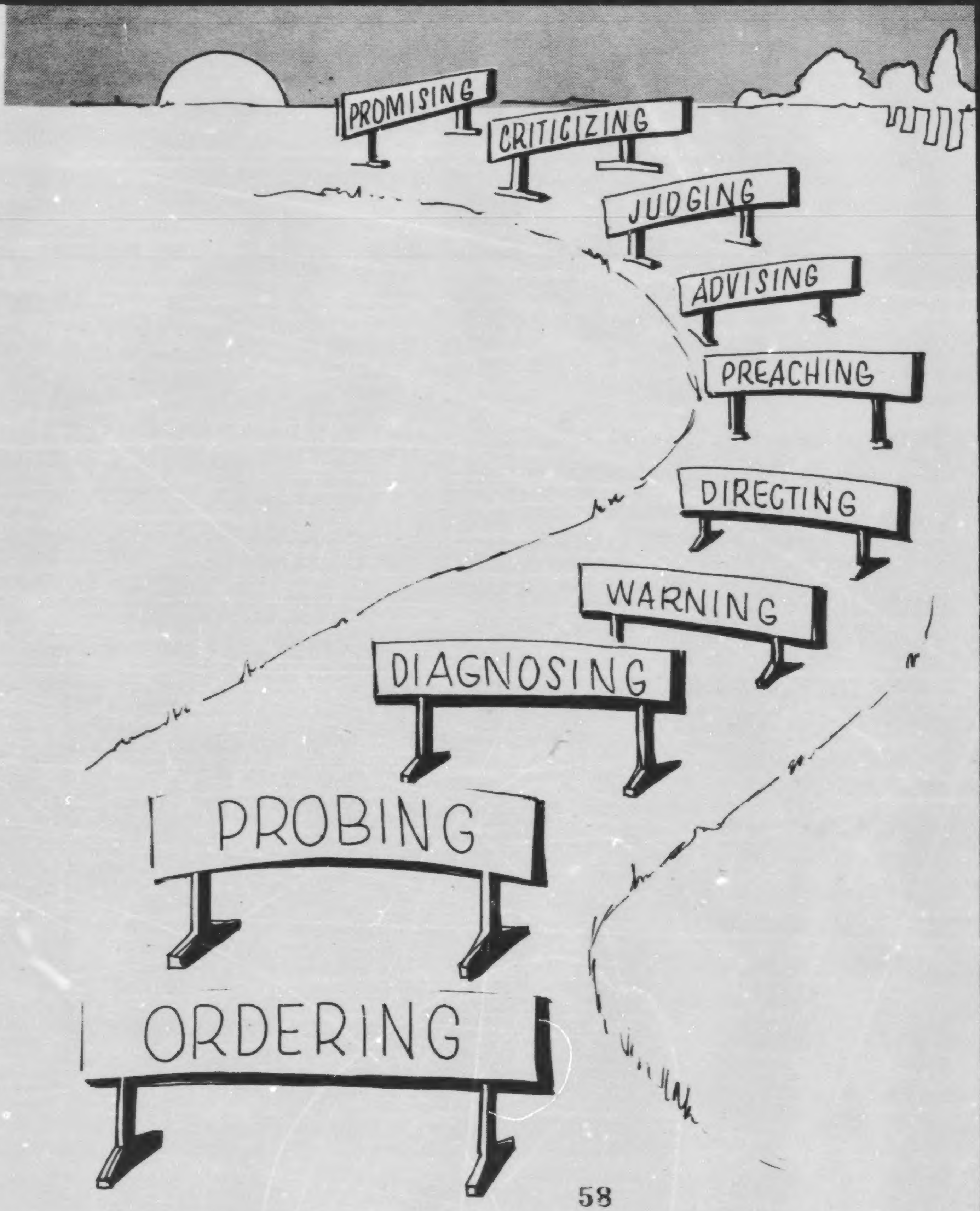
you are working with are only three or four years old, the parents may not have had time to reach the emotional acceptance stage. They may need defense mechanisms such as denial, regression or rationalization in the early days while they are adjusting to the shock and hurt of the news. The only way to help parents overcome the need for escape from reality is to permit them to express their feelings and fears openly and help them to find ways to cope.

By being responsive to the needs of parents, you can provide them the emotional and psychological support they need to move toward full acceptance of their handicapped child.

Be Empathetic. Avoid pitying the parent since no constructive solution will result from that approach. Raising a family is not an easy thing to do these days in the best of circumstances. All parents experience exasperation and frustration but handicapped children can be especially difficult to live with. All handicapped children are not lovable all of the time. Disorganized or hyperactive children can drive their parents to a state of exhaustion. Additional worries about financial costs for treatment and long-term care may add to their tensions.

If a parent says to you, "But you don't know what it's like to live with a child like this," answer truthfully. Admit to the parent that you don't know what it would be like to live with their handicapped child on a 24-hour a day basis, that there must be many difficult times and if they would care to tell you about it, you would do your very best to try to understand.

Be Realistic. Most children will show improvement after they have been in your program for awhile. This may be true because of any one of several


PROMISING
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ROADBLOCKS TO EFFECTIVE COUNSELING

factors or a combination of them: the developmental activities planned for the children, the resource help utilized, the opportunities provided for interaction with other children and adults or just because the children are older and have become more mature.

But, don't promise the parents more than you are sure you can deliver. Like all parents everywhere, parents of children with disabilities will have certain expectations and aspirations for their child, some realistic and some beyond the realm of realization. You will do the parents of handicapped children a disservice if you raise their hopes unrealistically. Because what you say may be what they want desperately to hear, they will tend to believe you, and then become bitter or disillusioned when it does not come to pass.

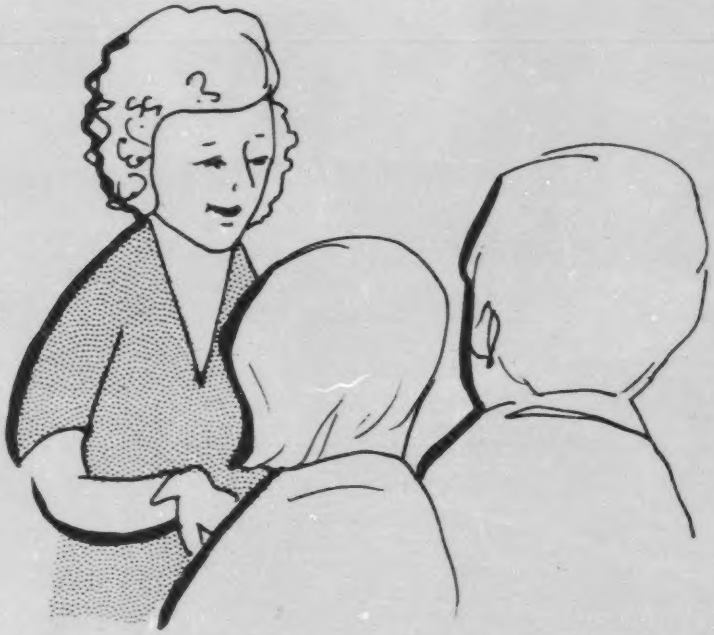
Often, parents of a child whose problems are mild find it difficult to accept the child's limitations, preferring to blame the child's slowness on lack of motivation or laziness.

On the other hand, parents may not realize that a child with several rather minor handicaps may have a more difficult time of it than a child with one serious disability because of the interplay of the problems.

Help guide the parents to realistic expectations. It will be just as harmful to the child for them to expect too little as too much. In Dr. Jenny Klein's words, encourage the parents and the staff to "provide experiences in which the child has to reach as far as he can without being frustrated."

Be Honest. The trusting relationship you want to develop with parents will only come about with complete honesty on your part.

Share the information you have learned about the child with the parents. There should be no secrets kept from the parents in the child's record.



There will be times when you will have to answer, "I don't know, but I'll try to find out." Even "experts" don't have all the answers. There may be situations in which you will have nothing to offer but moral support. There may be no program that truly fits the child's needs, or you may not be able to obtain the special services or therapy that would be most desirable. The parents may be disappointed, but being honest with the parents about the situation will bring you closer together. The parents may feel, often for the first time, that someone is on their side struggling to help the child. Contact with *people who understand* may give the parents the courage to continue working for the child's best interests.

Be Objective. The importance of maintaining a warm yet objective relationship with the parents cannot be overstated.

Your role is to help the family deal with the problems related to the child's handicap and special needs. It is not your position to solve all the family's problems for them. You may want to point out some of the alternatives or options open to them. Then let the parents come to their own conclusions as to the course of action they want to follow.

It will not be a service to the parents to permit them to become overly dependent on you or to use you as a decision maker in the areas of family concern which are their responsibility.

Be a Good Listener. Almost anyone who has a genuine concern for parents can learn to use his natural abilities to relate with parents. There is no magic formula. Successful styles are as varied as the personalities of the counselors, but there is one element common to all - the counselors are active listeners.

This quality is not as easy to achieve as it might seem. Being a good listener takes self-discipline, since there is a great temptation to tell what you would have done under similar circumstances or to offer advice.

After you have helped the parents to feel as comfortable and relaxed as possible, let the parents speak first and then really listen to what they have to say. An occasional nod on your part will let them know that you are listening. A concise restatement of what you understand the parents to say will insure that you are both working on the same wave length.

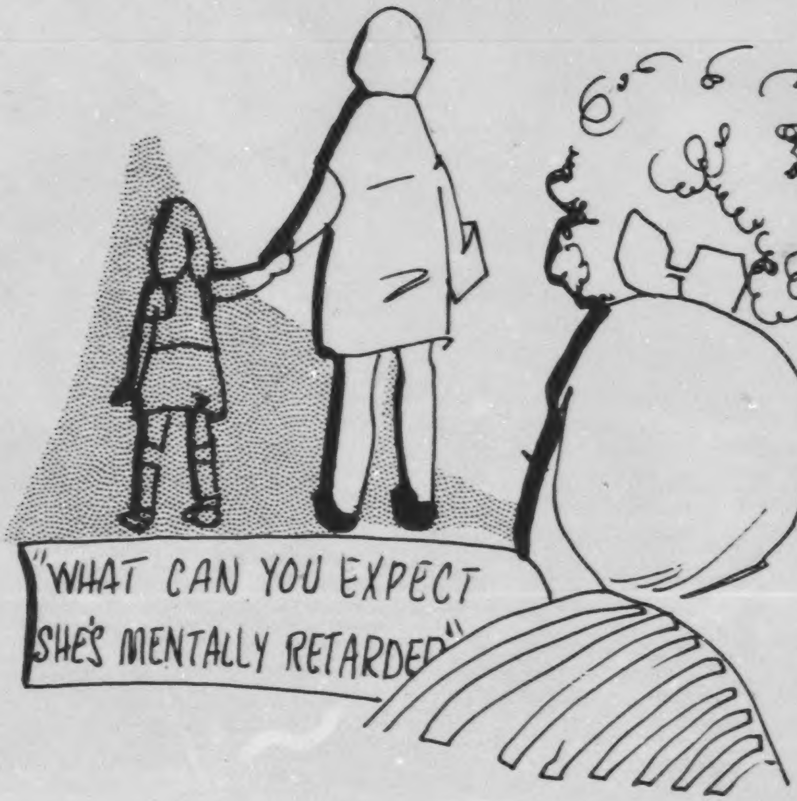
Don't be concerned about occasional lapses in the conversation. Moments of silence may mean that the parents are thinking ahead to what they want to say next. Don't let the silence make you feel uncomfortable. It's probably not as long as it seems, but if you break the silence with a question too soon or introduce a new topic, the parents' train of thought may be broken and the message lost.

Keep the lines of communication open between the center and the home in any one of a number of ways: send home handwritten notes of the child's new achievements or funny happenings, make a home visit, telephone occasionally to let the parents know you are thinking of them, take time for informal chats before or after school, and schedule regular conferences to exchange information about the child. This two-way sharing of information will benefit the child, the parents, and your program.

Be Knowledgeable About Normal Child Development. If you have a thorough understanding of normal child growth principles and the sequence in which children's skills develop, you may be able to relieve the parents of much unnecessary worry. Many annoying behaviors that a handicapped child displays are a natural part of growing up and occur simply because he is a child, not because of the handicap. Examples of this might be temper tantrums, a negative attitude, temporary disfluencies in speech (similar to but not really a stutter), fears, or imaginary playmates.

The parents will be able to provide a warmer, more supportive home environment for the child as their knowledge of normal child development improves.

Be Worthy of Trust. Parents have the right to expect that disclosures or conversations they have had with you will not become the subject of idle gossip for other parents, staff members or persons in the community. Building a relationship of confidence with a parent takes time. Don't jeopardize it with a thoughtless word.



Form a Partnership. Form a partnership with the parents so they are involved in the setting of goals for the child in the Head Start program and in the procedures to be used to attain those goals. In this way, there can be important carryover into the home. The child can only benefit from this consistent approach, and a well-planned program will strengthen the family's capacity to meet both their child's needs and their own.

Know Your Resources. Locating appropriate resources can be a most frustrating experience for parents of children with special needs. To give parents a Head Start, it is imperative that you become familiar with the services offered by organizations and agencies in your community and state.

Resources for specific handicapping conditions are listed at the end of each chapter in Part III of this manual.

Information about diagnostic, medical, and educational resources and the procedure for referral may also be obtained from the following agencies:

The State Office of Developmental Disabilities
The State Office of Mental Retardation
The State Department of Public Welfare
The State Department of Health
The State Department of Special Education

The parents may not be aware of the financial assistance available to them.

Some disabled children may qualify for regular income from Supplementary Security Income through the Social Security Office. This federal program is not the same as social security though some children who receive Social Security payments may also be eligible for S.S.I. Eligibility is determined by financial need as created by a disability.

- Eligibility for Early and Periodic Screening, Diagnosis and Treatment (EPSDT) is automatic to anyone whose family receives ADC. This also qualifies them for Medical Assistance. EPSDT allows for a full screening once a year by a physician of the family's choice, with recommendations for eyeglasses, hearing aids, dental care, innoculations, etc., followed through with the family by a representative from the Welfare Office. The thrust of EPSDT is two-fold: first to develop a habit of regular medical check-ups, and second, for early intervention treatment of any health problems. A few families who do not meet ADC guidelines because of an income slightly in excess of the requirement may still be eligible for Medical Assistance.

The parent may need encouragement to check with the local county welfare office. If a family does receive any type of welfare assistance, under no circumstances should they pay any fees. The Welfare Department will pay for any prescribed treatment, but will *never* reimburse the client for any bills he pays.

- The Welfare Office also administers a rarely used fund for intact families with an adequate income who face catastrophic medical bills such as a few handicapped youngsters may incur. This Emergency Assistance is not easy to get but can be a financial lifesaver if the family qualifies.

- Children of an active or retired military parent may be eligible for medical care for a physical handicap or serious illness (but not for educational handicaps such as learning disabilities or mental retardation) under the Champus Program. The CHAP Office, Offutt Air Force Base (402) 294-7305, will be glad to discuss the benefits available with military associated parents.

- Disabled and totally dependent children of railroad employees are entitled to benefits through Railroad Retirement. For further information call (402)221-4641, or write to Railroad Retirement, 215 North 17th Street, Omaha, Nebraska 68102.

- In Omaha, there are 29 census tracts established for Children and Youth (C & Y) Clinics. Anyone who is a resident of one of these tracts may register his children at the local clinic for medical and dental diagnosis and treatment.

- The Easter Seal Society provides information and service for individuals with disabilities based on need. They will purchase physical and speech therapy service, provide transportation to medical centers and assist financially with the cost of medical evaluation. They also operate a purchase-rental-loan equipment pool.

- Community service clubs may assist with the purchase of special equipment or cost of medical service.

- Parents should be advised to contact their local office of the Internal Revenue Service to find out about the tax deductions they are permitted to take for their handicapped child.

RECOMMENDED READING

For Parents

Spock, Benjamin and Lerrigo, Marion. *Caring for Your Disabled Child.* New York: Collier-MacMillan Publishers, 1968. ($1.98)

Wentworth, Elise H. *Listen to Your Heart: A Message to Parents of Handicapped Children.* The Exceptional Parent Bookstore, P. O. Box 902, Manchester, N.H. 03105 ($6.95)

The Exceptional Parent Magazine, P. O. Box 964, Manchester, N.H. 03105 One year subscription (6 issues) $10.00

For Staff

Granato, Sam and Krone, Elizabeth. *Day Care #8: Serving Children with Special Needs.* Office of Child Development, U. S. Department of Health, Education and Welfare.

Ginott, H. *Between Parent and Child.* New York: Avon Books, 1971.

Murphy, Lois B. and Leeper, Ethel M. *The Vulnerable Child.* No. 5 Caring for Children Series. Office of Child Development, U. S. Department of Health, Education and Welfare.

McDonald, Eugene T. *Understanding Those Feelings: A Guide for Parents of Handicapped Children and Everyone Who Counsels Them.* The Exceptional Parent Bookstore, P. O. Box 902, Manchester, N.H. 03105($5.95)

Chapter 9

PARENT INVOLVEMENT

Sam Delaney

Rationale for Involving Parents

Parents can be trained to become effective teachers of their handicapped child. In fact, parents of handicapped children often ask their child's teachers *how* they might best utilize their energies to benefit the child. Teachers recognize that the parents' energies can also be channeled so as to enhance their self-image as parents.

But sometimes parents are unable or hesitant to ask directly for training. As a result, their plea for assistance may be couched in discussions about the child's behavior and, specifically, in expressions of concern about his limited progress at home or in the Head Start center. Teachers can use these discussions to open the way for parent training.

Parents are responsible for seeing that their child's special needs are met daily, and yet this is a responsibility for which they have received little, if any, formal training. It seems only reasonable and fair to show them how to provide an environment with opportunities for the child's maximum development.

Teachers of handicapped children have long realized that these children require more teaching time than can be offered in the classroom. One solution is to train parents to provide additional educational and social opportunities in the home. This can help to insure continuity between teaching programs in the school and the home. This may be especially important if the child is in a program that does not operate in the summer. During these times, parents can help the children to maintain and even accelerate the gains that they have made during the school year. Without a home program in the summer, progress may be lost.

Another important reason for involving parents of handicapped children enrolled in Head Start is that these programs will end when the child enters kindergarten. Trained parents can provide an ongoing program of educational experience in conjunction with the child's kindergarten or first grade teacher.

Evidence produced in research studies clearly indicates that the family can most effectively and economically foster and sustain a child's development. The success of any intervention program designed to meet the special needs of a child is dependent upon the family's involvement in the program. For this reason, the Office of Child Development has called upon Head Start programs to acknowledge the important role of the parent and to develop experiences that will enable parents to become effectively involved in parent-child intervention programs aimed at meeting the special needs of their handicapped child.

Parents and Their Needs

Head Start staffs charged with this responsibility must have a fundamental understanding and appreciation not only of the child's special needs but also of the parents' needs. Parents must be appreciated for their individual qualities and gifts. All too often, parents are lumped together in a single category--"the" parents.

THE PARENTS

For instance, staff members may go to great pains to individualize instructional programs and activities for children in the classroom, but fail to do the same for the parents. As a result, the same few parents continue to appear at the monthly meetings or participate in the classroom activities. Other parents never attend meetings or work in the classroom. How many times have Head Start teachers told themselves, "The next meeting will be better attended; if it weren't for the nasty weather, they would have been here tonight."

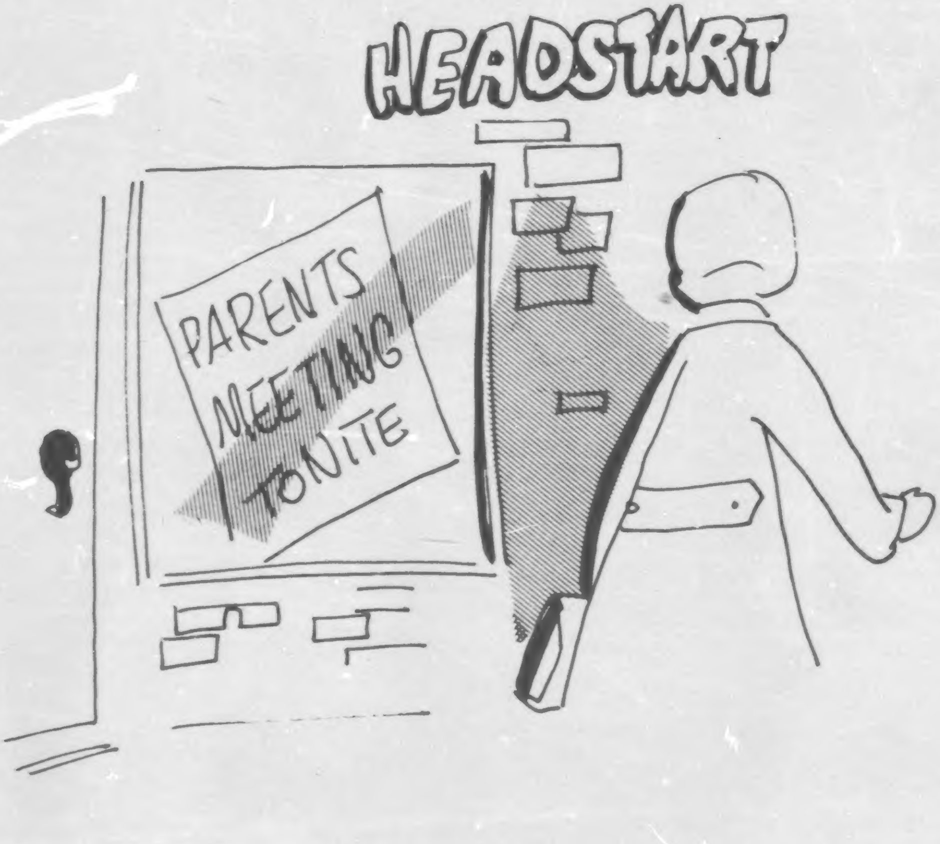
Parents need to be treated as individual human beings with unique needs. For instance, some parents operate very well in large groups, yet others "freeze at the controls" in these groups.

Parent involvement coordinators and teachers should identify the most effective way of communicating with every parent. Each parent meeting should be designed to convey information that will further enhance the parents' involvement with their child.

Parents' needs are not only unique, but they are as varied as the needs of children in the Head Start classroom. Educational opportunities and experiences must be based upon these varied needs if they are to have any significance for the parents involved in the parent training program.

Needs Assessment

A careful needs assessment should be conducted when a program is developed for a child; it seems only logical to do the same for the parents. Children exhibit behavior problems when their needs are not met or they "tune out." Parents also "tune out" to training that is not based on their needs--they simply do not participate.



When parents are asked to perform tasks that they had not been prepared for, they may not even try to do them. So it's obvious that one must assess the individual needs and skills of the parents if one hopes to involve them meaningfully.

"Teaching to the middle" - that is, to some imaginary "average" student is no longer acceptable practice in educating young children. The same is true for parent training programs: it is unacceptable to attempt to teach "the" parents when we know that there is no such thing as an average parent.

A positive approach will help the parents arrange the child's home environment so that he can perform and participate in all activities as normally as possible. For example, if the child is orthopedically handicapped, the parents could arrange the furniture and other physical objects in the home in a way that enables the child to move as freely as possible without harm. By emphasizing what *can* be done at home to help the child, the teacher-parent involvement or social service coordinator can help the parents over a big psychological hurdle: instead of dwelling on the child's handicap, they can focus their energies on ways of reducing its impairing effect.

The Training Program

Given the individuality of parents' needs, mentioned earlier, it would be foolish to try to spell out a training program that would be applicable for every parent and every child.

However, we *can* identify certain elements that should be present in any training program designed to help parents become effective teachers of their handicapped preschool child.

Appropriate introduction to the program. The manner in which parents are introduced to the training program is critical to the success of the program. The introduction should enable parents to relate to the program's goals, procedures, and evaluative efforts without anxiety or a great deal of exertion. Trainers should be aware of the understanding that the parents have and base their introduction to the program upon this information.

Maintaining appropriate behavior towards the parent. Functional language should be used in working with parents, particularly in the introductory stages of the parent-child intervention program. This does not mean that parents should be spoken to in a patronizing manner. Rather, it means that the trainer's language should convey information that the parent requires without losing the parent's interest in the process. Further, trainers should be aware that the parents have made a number of sacrifices in order to attend the training session. Such recognition helps the trainer to realize that he or she is working with responsible human beings who love their children and are deeply interested in their growth and development.

Establishing realistic and measurable goals. A third aspect critical to the success of the training program is that of allowing the parents to specify or define the goals that they wish their child to attain. The trainer should help the parents to identify goals that are realistic and developmentally appropriate for their child. Goals that have been identified should be measurable. Trainers can be very helpful by assisting parents to specify their goals for the child in terms of behavioral objectives. Because behaviors leading to the objectives can be measured, parents and teachers can determine whether or not the child is attaining or approximating the objectives that have been established. If the child is not attaining these goals, parents and teachers know that the program may need to be changed.

Parents may also wish to establish training objectives for themselves. A sensitive teacher will acknowledge the parents' progress towards training goals and make the parents aware of their increasing competencies.

Consistency. If there are two parents in a family, the trainer should be certain that both parents are in agreement about the goals and objectives established for their child. To do so is to provide another element that is critical in the program--consistency. If parents are to be consistent in the procedures that they develop and employ, they must first be consistent in the goal that they have specified. In asking the parents to agree upon the goal, the trainer is also verifying the need for intervention in a given area. What might be a problem for one parent may not be considered a problem by another.

Data collection. Very often, a trainer can assist the parents by asking them to count the times a child does or does not do something that they are concerned about. In collecting data, parents have an opportunity to validate their concerns. For instance, they may find that although they thought Johnny *never* obeyed them, he really does obey them more often than not. That gives them a chance to look more closely at the occasions when he does not obey them, and to find out whether there is something about these situations that can be changed.

Learning how to keep accurate counts of children's behavior is an excellent introduction to the skill of data-taking, a skill that parents may wish to continue using as they become more and more effective teachers of their children.

Developing appropriate procedures. Once the parents have specified the desired behavior and have documented the need for a program, they can move into developing a number of appropriate procedures designed to assist the child to attain the specified objectives.

Procedures should be developed in such a way that the parents are actually the ones who discover a number of the "ideas" that they might employ in assisting their child. Parents will identify with a program when they have significantly contributed to its development. *The most important consideration is to establish procedures that the parents can live with.* To develop procedures that are incompatible with their wishes or needs would be disastrous.

Enabling the parents to experience present and future success. Parents need to experience success as much as the child does. Parents can be trained to observe and take data that will enable them to determine the effectiveness of their program, and to experience success as their program yields desirable results.

As the child develops, his needs will change. Parents who have been trained to identify these needs through observation and measurement will be in an excellent position to continue this work--developing procedures to meet their child's special needs, and evaluating the effectiveness of these procedures.

To provide parents with this ability is to provide them with an opportunity to increase the desirable behaviors in their child's repertoire, as well as to reduce his undersirable behaviors. Most important, such training provides them with skills that can increase their effective interaction with their children.

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Honig, Alice S. *Parent Involvement in Early Childhood Education.* 1975
Order from: National Association for Education of Young Children
Publications Department
1834 Connecticut Avenue, N.W.
Washington D.C. ($3.00)

King, Clarita A. (Ed.) *Group Activity Plans for Training Parents of Handicapped Children.* West Carolina Center. 1975.
Order from: Clarita A. King
West Carolina Center
Enola Road
Morgantown, North Carolina 28655 ($2.50)

Weber, Susan J. *Portage Guide to Home Teaching.* 1975
Order from: Portage Project
Cooperative Educational Service
Agency 12
412 East Slifer Street
Portage, Wisconsin 53901 ($4.95)

Working with Families: A Manual for Developmental Centers in Handicapped Children in Head Start Series. Chapel Hill Training-Outreach Project.
Order from: Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091

Part III

Chapter 10

GIVING A HEAD START TO PARENTS OF CHILDREN WITH VISUAL IMPAIRMENTS

Mary Anne Karstens

> Education must aim at giving the visually impaired child a knowledge of the realities around him, the confidence to cope with these realities, and the feeling that he is recognized and accepted as an individual in his own right.
>
> Berthold Lowenfeld

As a mother of a blind child and later as a teacher of visually impaired children, I have struggled with the above statement. It expresses the total idea of what parents and educators are trying to accomplish with the visually impaired children entrusted to us. How do we go about accomplishing those goals?

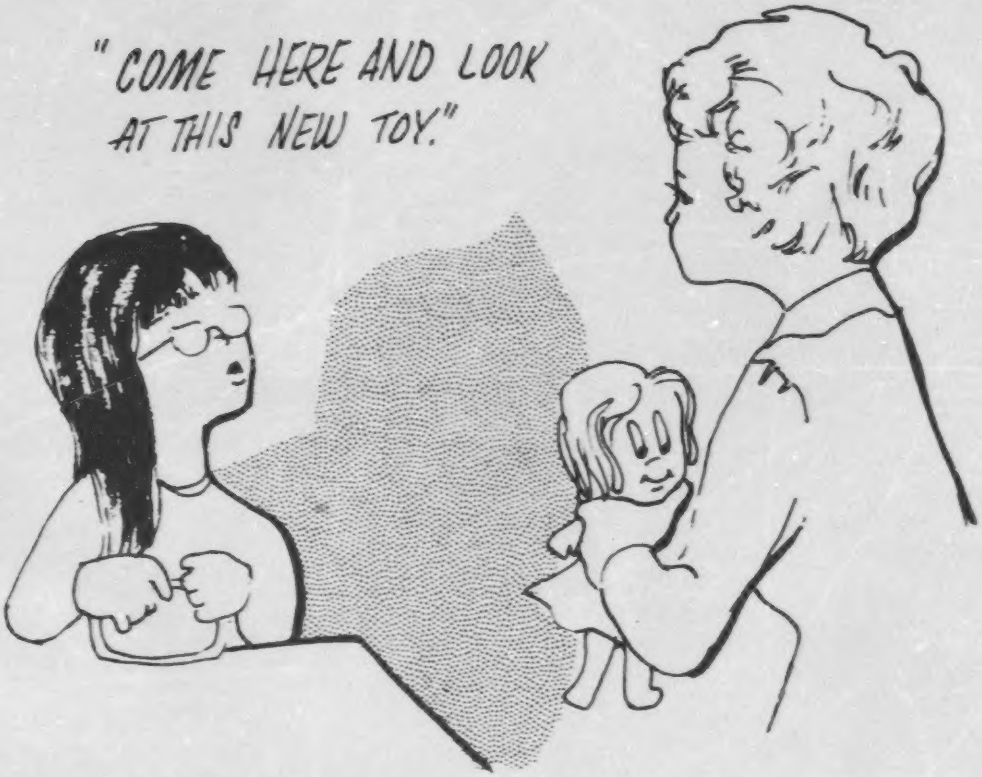
Statistics and Definitions

The 1966 findings of Jones and Collins regarding the number of blind or visually impaired children in the United States have held up quite well. "Visually handicapping conditions occur in about 1 out of every 1,000 children of school age." Therefore, it can be assumed that there are now about 50,000 to 55,000 visually handicapped children who require special education services.

Traditional definitions of blindness and of partial-sightedness have been based on acuity and/or a narrowed visual field. Both definitions are based on what the normally sighted person might see at a given distance. Children with a visual acuity of 20/200 or less were considered blind, whereas those who had a visual acuity better than 20/200 up to and including 20/70 were considered partially seeing. The 20/200 division also determined whether a child should be taught to read Braille or print (usually large print). As a result, many children with borderline vision would end up either reading braille with their eyes instead of their fingertips, or reading regular print--against the rules of the school and behind the teacher's back. As ophthalmologists began to question the concept of "saving" sight by not using it, the conclusion was reached that normal use of the eyes, even of a defective one, in most cases does no harm. Children are now encouraged to place their reading matter as close to their eyes as necessary, and to use magnifiers whenever feasible. Large print textbooks are used very effectively in the classroom. So, let it be known that while a formal medical definition is important, those working with the child on a daily basis may make a more valid evaluation of his functional vision. Those with even the slightest vision can be helped to use what vision they possess with increasing effectiveness. If these youngsters receive no help in putting to use what vision they have, their visual ability will deteriorate.

Teaching

Visually impaired boys and girls must be systematically introduced to their world. Things learned casually through visual means must be consciously taught when vision is limited.


"COME HERE AND LOOK AT THIS NEW TOY."

Do use the words "look" and "see" in a natural way in talking with the child. (Example:--"Come here and look at this new toy.") He will use his hands instead of his eyes, but he is accomplishing the same purpose.

The child must get ideas about other people, how they are reacting, how they are feeling and what they are doing through their voices, rather than from facial expressions, gestures or from eye-to-eye contact. Instead of gestures and facial expressions, an audible version may be substituted. (Example: Whan a mistake has been made, just a frown won't do. You might say, "We will have to help you learn to do that better, Bill.")

Children normally learn better when they watch and hear how to perform a new task and then do it themselves. Visually impaired children depend far more on this method of learning. For example, they must watch and listen as they are shown how to use a new tool. Put the child's hand on your hand as you hold the tool or have him hold the tool as you encompass his hand while the two of you together cause the tool to perform its function. As the tool is used, verbal description of a conversational sort explains the actions. All the while, try to make it an enjoyable experience.

There seems to be a "right" time for learning which varies from child to child. Numerous attempts over periods of time and frequent repetitions are necessary for learning to occur. Remember that what children do and think begins with the simplest and moves to complex.

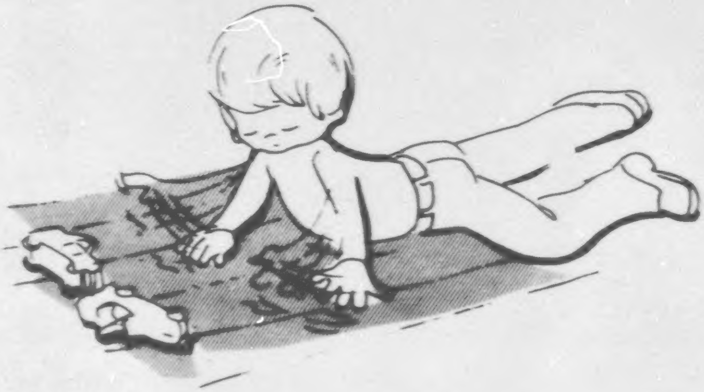
Independence is of vital importance to a visually impaired child. The natural tendency is to do things for this youngster. It will take a concentrated effort on the part of teachers and parents to control this urge. If the child is to grow into a productive adult, he must gain the skills, knowledge and attitudes which make independence possible. Within the bounds of good sense, every person should be shown how to do for himself those things which make him feel self-confident and capable of managing his world. Each must also learn when help from others should be sought. The child must learn to ask for help in a way that enables him to keep his self respect, and he must learn to be alert to ways in which he can offer aid to others in areas where his abilities are sharpest. There is a story of a 12-year old blind boy, who when camping with a group of sighted boys, delighted his buddies by going out in a rainstorm at night to let down the canvas flaps over the windows. Since he needed no flashlight, he could use both hands to untie flaps. What a hero!

Counseling the Parents

The terms "visually handicapped" and "blind" can be scary ones for parents. They may also be confusing, since they include a range from those children who do not see at all to those who may see rather well but are confused by what they see because of changes or distortions. It is important to reinforce the point to parents that, regardless of how their child sees, he is much like other children in terms of basic needs and feelings and in general responses to growth processes. He is an individual.

It is often hard for parents to be honest with a child about his vision. Be truthful with the child, without burdening him with too much technical information. It is not really kind to allow him to expect the sight he never will have. Instead, teach him the truth about his vision, but at the same time teach him to expect to lead a normal life by using alternative techniques. (Example: Examining an article by touch rather than by sight.) Once the child understands his vision problem, drop the subject.

The parents need not change their life-style for the blind or partially sighted child. A coffee table in the living room need not be moved, but the child can be taught where it is. One thing that is a hazard for blind children is half-open doors. The family must learn to either leave them wide open, or shut. Make that visually impaired child a real part of your family, sharing in household responsibilities even though it takes much effort on his part and on the part of those around him. Teach him to identify objects and textures by touch, and to name and describe things correctly. Help him to organize his belongings and keep track of where they are. If he must hunt for lost items by himself, he will learn quickly. A technique he may use to



search for a dropped item is to start with a small circle of the hand on the floor. Keeping the hand in touch with the floor at all times, widen the circle until the object is found. Other people should avoid moving his things without his knowledge. When you have rearranged the living room, take the child on a tour of the room, relating the furniture to a doorway that the child is familiar with.

One final thought for parents of visually impaired children: While it is important to think ahead and have expectations for your child, do not dwell on how this will all happen. Instead, look at this year, this month, and concentrate on teaching him the skills he will need today. If you do this, day in and day out, his development will proceed normally. And as each year passes and your child continues to grow and become an independent person, you will relax and have more confidence in your abilities as parents of a visually impaired child.

RESOURCES

Omaha Public Schools
Program for the Visually Impaired
3912 Cuming Street
Omaha, Nebraska 68132

Nebraska School for the Visually Handicapped
824 Tenth Avenue
Nebraska City, Nebraska 68410

Radio Talking Book
Tech High School
3219 Cuming Street
Omaha, Nebraska 68132

Regional Library for the Blind
1420 P Street
Lincoln, Nebraska 68508

State Services for Visually Impaired
City National Bank Building
Omaha, Nebraska 68132

American Foundation for the Blind, Inc.
15 West 16th Street
New York, New York 10011

Instructional Materials Reference Center for Visually Handicapped Children
American Printing House for the Blind
1839 Frankfort
Louisville, Kentucky 40201

National Society for the Prevention of Blindness
79 Madison Avenue
New York, New York 10016

RECOMMENDED READING

For Teachers

Creative Arts and Crafts. (A resource guide for those concerned with teaching of arts and crafts to visually handicapped children.) Louisville, Kentucky: Instructional Materials Reference Center.

Suggestions for Dealing with the Problems of the Visually Handicapped Preschool Child. The Michigan School for the Blind, 715 West Willow Street, Lansing, Michigan 48906.

Moor, Pauline M., A *Blind Child, Too, Can Go to Nursery School.* New York: American Foundation for the Blind. ($ .25)

Handbook for Teachers of the Visually Handicapped. (A service for the beginning or inexperienced teacher of the visually handicapped.) Louisville, Kentucky: Instructional Materials Reference Center.

For Parents

Ulrich, S. *Elizabeth.* Ann Arbor: Michigan Press, 1971 (A personal account of a mother's successful interaction with her blind child.)

For Parents and Teachers

Halliday, Carol. *The Visually Impaired Child, Growth, Learning, Development Infancy to School Age.* A booklet on current thinking of leaders in fields of child development and visual impairments. American Printing House for Blind, 1839 Frankfort, Louisville, Kentucky 40201.

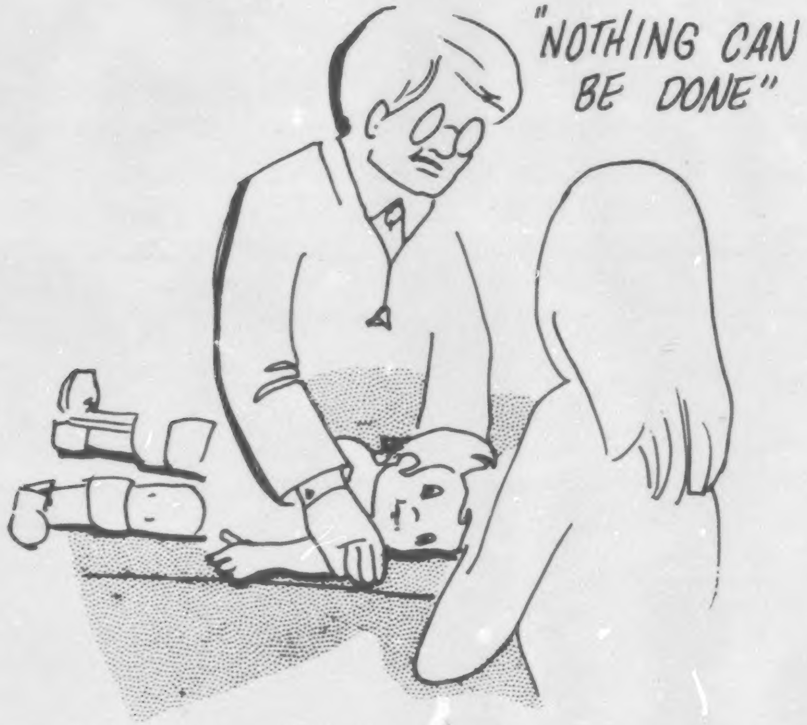
Chapter 11

GIVING A HEAD START TO PARENTS OF CHILDREN WITH HEARING IMPAIRMENTS

Weslee D'Audney

Parents, and particularly mothers, often suspect something is wrong with their hearing impaired child months or even years before their suspicions are confirmed. They may not be able to pinpoint the cause of their disquiet, but the feeling persists. It may stem from the fact that perhaps the baby doesn't look them in the eye when they talk to him. (A deaf infant, not hearing sound, will watch whatever is moving: his mother's hands or lips.) Or the child may not respond with a reinforcing smile when his name is spoken as other babies do. These are subtle symptoms that only the very observant parent will pick up, and even then the significance of the symptoms may not be understood. Unlike a physical disability or most cases of blindness, a hearing loss in a young child is difficult to detect and rarely looked for in a routine medical examination. Few hospitals check the hearing of infants in the newborn nursery, and all too many doctors omit tests of hearing, even when the child has evidenced change in behavior following a disease such as meningitis, mumps, scarlet fever, measles, whooping cough or abscesses of the ear--all of which are known to cause hearing loss.

Consequently, the child's hearing loss may go unidentified. The parents' fears gnaw away at them as the child grows. Could their child be mentally retarded? Emotionally disturbed? What is it that is different? Many parents are almost relieved to finally get the diagnosis of deafness.



The critical time for counseling is right after the diagnosis is made, but in many cases the parents are told, "Nothing can be done. Wait until he's five or six and then send him to the deaf school in Omaha." Other parents are unnecessarily confused by conflicting advice from well-meaning professionals pushing *their* preferred method of instruction for deaf children. Almost all parents have, at one time or another, been consoled by reassuring friends and family members with statements such as, "They can do wonderful things for them now." Or "Just look at Helen Keller." These statements do nothing to ease the pain of the parent or help the child.

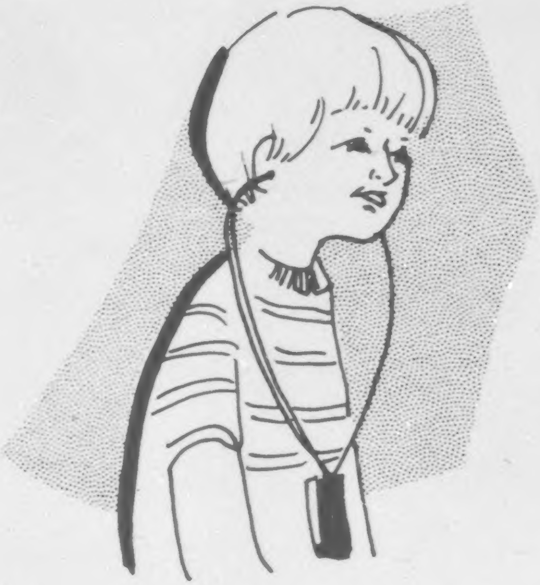
The cause of the loss, while important for the family to know and of academic interest to the counselor, will not be of prime concern to the Head Start staff working with the child and the family. The important thing is the degree of loss and what can be done either to correct or ameliorate the condition. The sooner positive steps are taken, the faster the child will progress and the better the parents will feel. Depending on the severity of the loss, the hearing impaired child will be classified as either hard of hearing or deaf.

The Child Who Is Hard of Hearing

Most children who are hard of hearing have a conductive loss. Something prevents the sound from reaching the inner ear, which is responsible for relaying the sound message to the brain. This may be caused by a simple build-up of wax in the ear, or a more serious build-up of fluid in the middle ear caused by an infection or a deformity of the ear, the ear canal, or the tiny bone in the middle ear.

A conductive loss can often be cured or greatly improved through medical treatment with drugs or surgical procedures.

Children who are hard of hearing have usable, functional hearing and a suitable hearing aid should be fitted as soon as possible. The parents and the Head Start staff working with the child should be trained in caring for and checking the hearing aid. Just because the child is wearing an aid does not mean that the aid is functioning at top efficiency or working at all.



The hearing aid will not give a hard of hearing child perfect hearing. However, he will be a most likely candidate for successful integration into the Head Start program and public school later on. The child may need the services of a speech therapist to teach or correct some of the sounds he mispronounces because he does not hear them clearly.

The educational outlook for the hard of hearing child is excellent if only he receives a little extra consideration from those around him. The hearing aid will not provide natural sound, although it certainly does help in listening situations. Unfortunately, it is not selective and amplifies *all* sounds---not just speech sounds. Sound is reflected from hard surfaces such as tiled floors and windows and causes feedback. A carpet on the floor will help absorb the bounce-back of sound and will reduce the amplification of sliding chairs and footsteps.

The Child Who Is Deaf

The effects of a profound hearing loss may be misunderstood by parents, teachers and professionals. It is a triple handicap to the child deaf from birth or deafened before speech had developed. Not only can he not hear, but he will not develop language or learn to speak without special intervention.

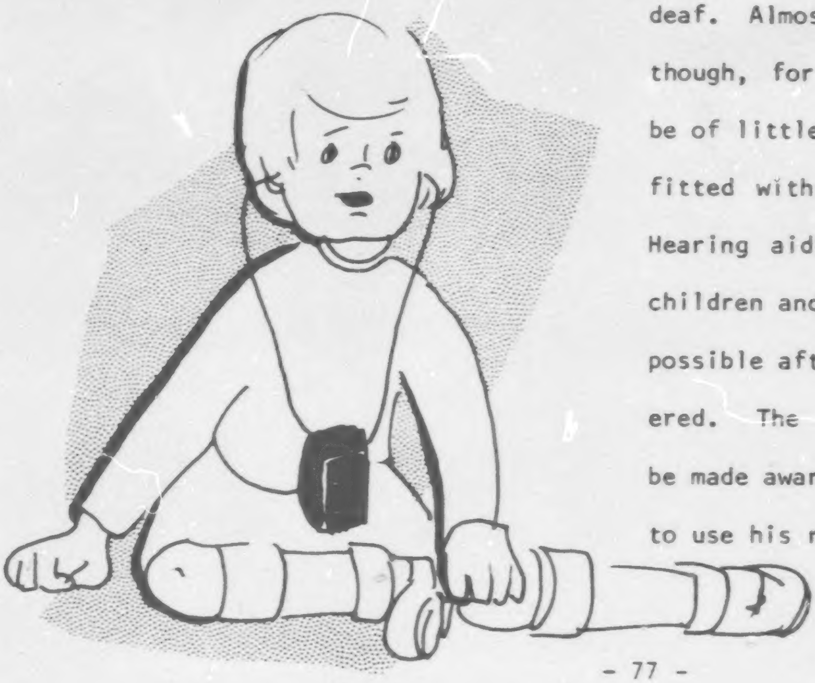
While the child deaf from birth does not experience deafness as a loss, as we who have heard would, it does drastically alter his contacts with the world and all the people in it.

The isolation imposed by deafness engulfs not only the child but the whole family circle. The mother may be at a loss as to the best way to handle a child with whom she cannot communicate. The child may be taking his feelings of frustration out in frequent temper tantrums. With the advent of communication skills, things will get better, but the frustrations and psychological implications caused by the deafness for both the child and the family will not be resolved easily.

A baby who is deaf looks and acts like any other baby. A toddler who is deaf may be a little late in sitting and walking (motor skills that require balance), but he'll flit happily from one thing to another busily exploring, touching, tasting and looking. It is only when other children his age start talking, following commands, and asking questions that the true impact of the disability hits home.

Most profound deafness is a sensori-neural loss. The problem lies in the inner ear or in the auditory nerve. The deafness may be the result of maternal rubella, certain life-saving drugs, disease, Rh factor, or it may have a genetic origin. Deafness is also frequently associated with prematurity. In many cases, the cause is unknown. At present, the condition is not correctable. Parents should not be given the false hope that the child's hearing can be restored through acupuncture, pacemakers implanted in the brain, or other devices. Exciting research into ways of stimulating the auditory nerve is being conducted at several medical centers. As of this writing, no magic panacea has been found.

It is the rare child who is totally deaf. Almost all have some hearing, although, for practical purposes, it may be of little use until the child has been fitted with one or two hearing aids. Hearing aids are imperative for deaf children and should be fitted as soon as possible after the loss has been discovered. The child who is deaf must first be made aware of sound and then taught to use his residual hearing.



Some parents tend to be over-optimistic and think that the hearing aid will solve all the child's problems. It won't. If the loss is profound, even with special early training and a hearing aid, the child will have difficulty learning language and his voice may have an unusual tone.

The deaf child has difficulty learning to talk simply because he does not hear. There is nothing wrong with his vocal cords or speech mechanism. The unfortunate label of "dumb," as it is applied to the deaf, is defined in the dictionary as "lacking the faculty of speech." Some people incorrectly think this means that deaf people are stupid. Hearing impaired children have essentially the same distribution of intelligence as the hearing population. Some are brilliant, most are of average intelligence, and some are slow learners.

The parents' primary concern is, "Will my child be able to talk?" There are many factors that will influence the child's ultimate development of understandable speech.

Age at Onset

The child with acquired deafness who has heard normally for the first one, two or three years of his life will have an advantage over the child deaf from birth.

Amount of Residual Hearing

The more hearing the child has, the more likely he will be to develop understandable speech.

Age at Diagnosis

The sooner the hearing loss is diagnosed, the sooner the child can be fitted with a hearing aid and trained to use it.

Early Intervention

The optimal time for language development is in the preschool years when hearing children learn language naturally. Ideally, a hearing impaired child's special program would begin in infancy with educational support for the parents. For children who are deaf, more than for any other type of handicap, the preschool years are of vital importance. These children need specialized help. The main emphasis should be on auditory training and language comprehension.

If the family lives too far away from special services, do recommend they enroll in the John Tracy Clinic Correspondence Course. It consists of a series of twelve lessons covering a wide range of topics, from the use of hearing aids to toilet training.

In addition to specialized training, the child who is deaf will benefit greatly from the Head Start experience with hearing children.

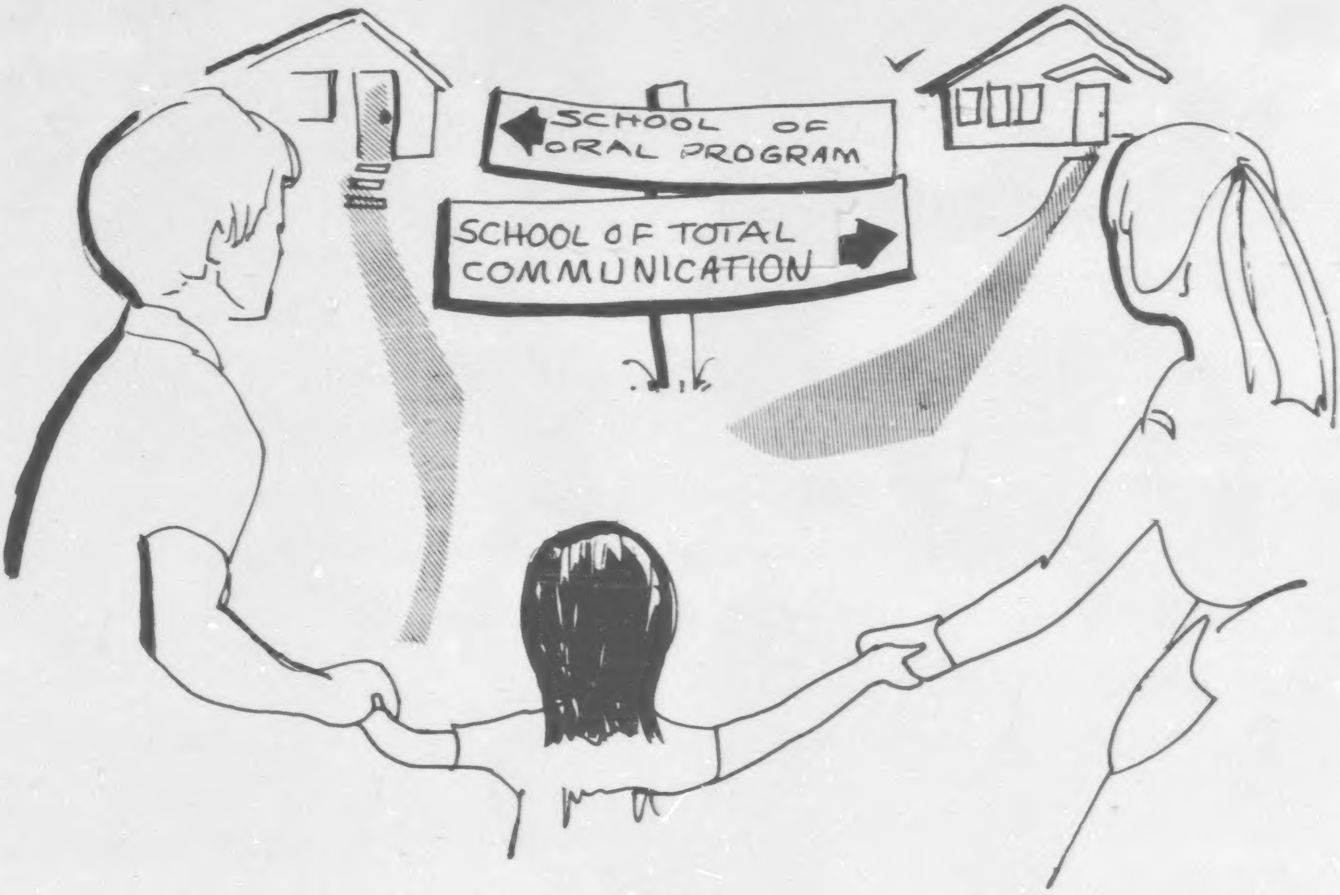
Cooperation of Parents

Few parents will have had previous experience with deafness, so most will require specific direction and training before they understand how a hearing loss influences every aspect of the child's intellectual, social and emotional growth.

Parents can accomplish much with their own children with a little bit of help from specialists. The parents will need to learn the principles of language development and how to capitalize on every opportunity for teaching language. It's not easy to talk and keep talking to a child who can't hear, but that is what must be done. Dr. Redell, director of the San Francisco Hearing and Speech Center, claims, "Behind every deaf child who has learned to speak well there stands a persistent adult, usually the mother."

On the other hand, Dr. Harold D. Love, author of *Parental Attitudes Toward Exceptional Children*, cautions that "parents of deaf children, in particular, need help in avoiding the strains of being overly conscientious and self-conscious about their responsibility as parents. They need encouragement to relax and enjoy their children. The other children tend to be short-changed in a family with a deaf child."

There is a low incidence of deafness among young children, therefore, special schools and classes are generally found only in metropolitan areas. The child may have to live in a residential center away from home when it is time to go to school. Some well-adjusted deaf children with a foundation in language may successfully attend a regular school if a resource teacher is available.



The parents will have a difficult decision to make in selecting the method of instruction for their child. There is much controversy among professionals in deaf education. Some educators are dedicated to the aural-oral method which bases instruction solely on speech, speech-reading, and the use of the child's residual hearing. Others endorse total communication which incorporates all methods of communication, including the use of speech, speech-reading, residual hearing and, in addition, gestures, signs and finger spelling. The parents should be encouraged to visit classes for the deaf using different methods of education and to talk to deaf adults, the child's audiologist and speech therapist, and deaf educators. The decision should be based on the method best suited to their child.

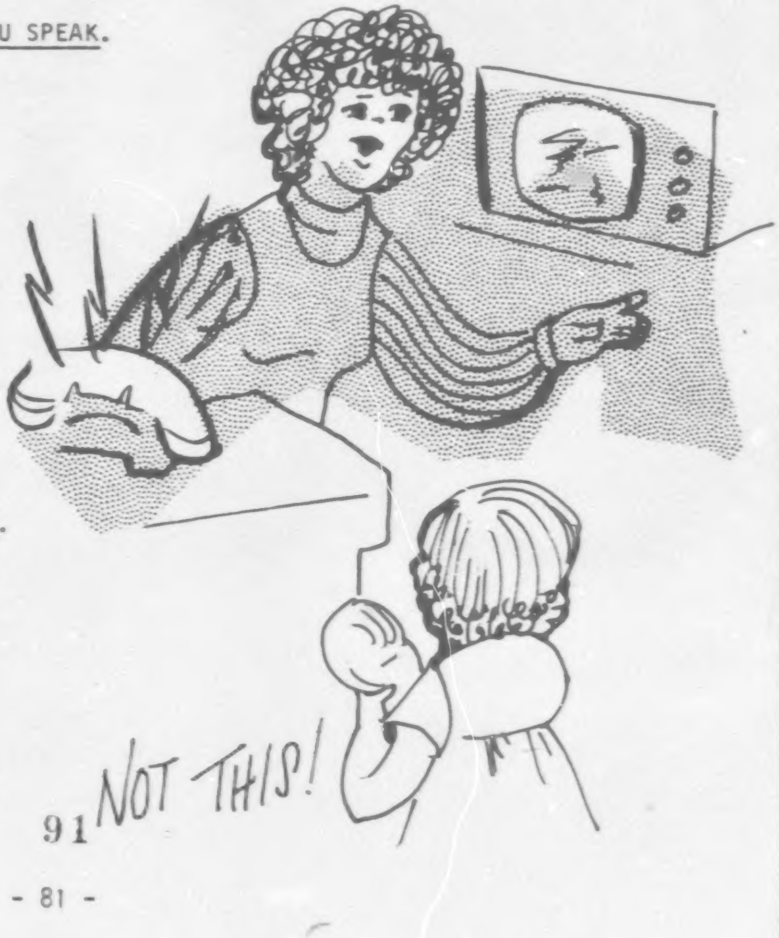
GENERAL ADVICE FOR COMMUNICATING WITH HEARING IMPAIRED CHILDREN

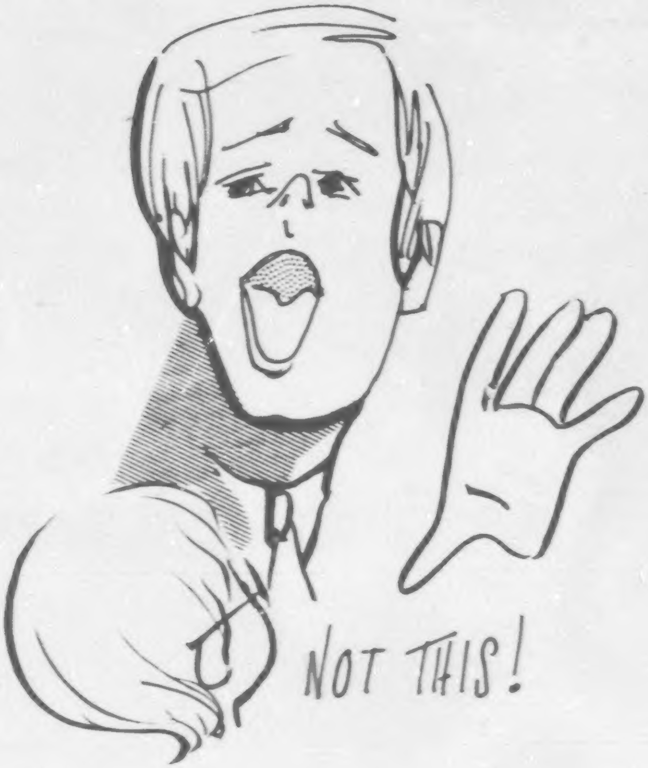
MOVE CLOSE TO THE CHILD WHEN YOU SPEAK.

Not for the sake of added loudness, but to make your speech clearer. The farther sound has to travel, the more chance it has to mix with other background noise in the room.

SPEAK IN A NORMAL TONE OF VOICE.

The hearing aid will do the job of amplifying what you say, so you don't have to shout.





SPEAK NATURALLY.

Exaggerated lip movements make it much more difficult to understand speech.

SPEAK SLOWLY.

You will automatically speak more clearly and will also give the child more time to figure out what you are saying to him.

FACE THE CHILD DIRECTLY WHEN YOU SPEAK.

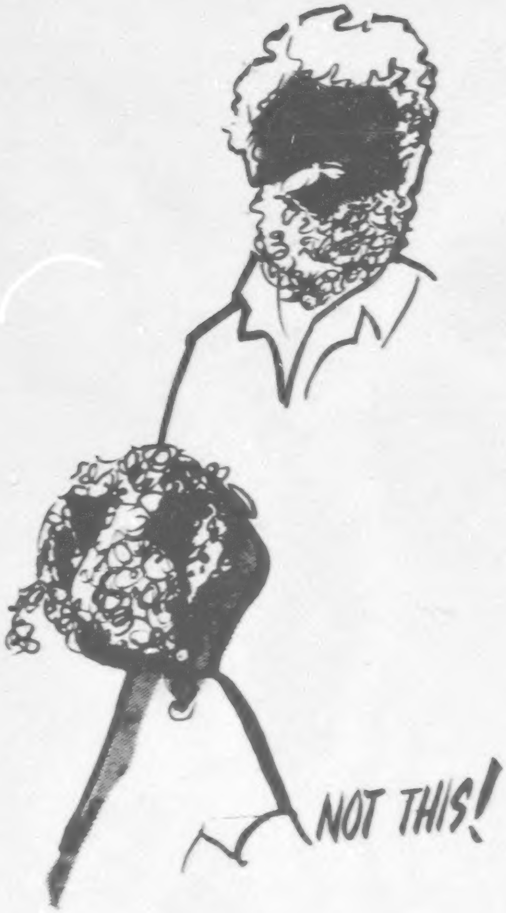
This will give him the best chance to read your lips and take advantage of the clues offered by your facial expression and gestures.

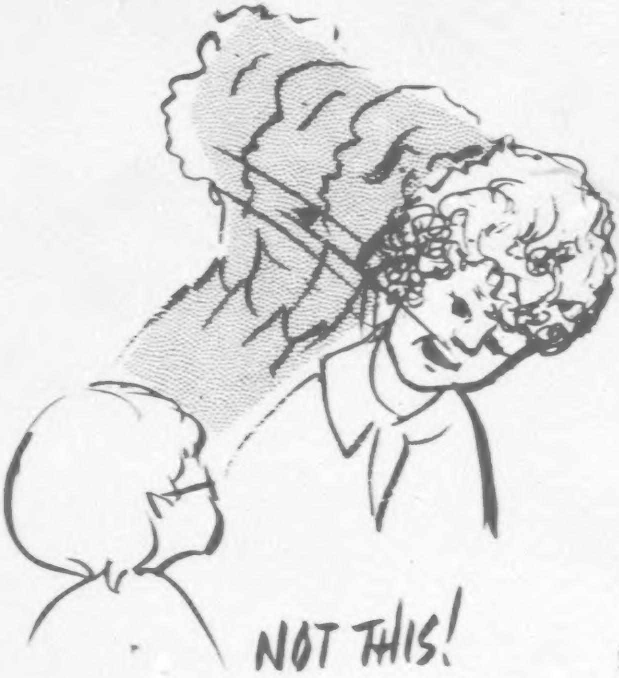
GET DOWN TO HIS LEVEL.

Make sure that he can see your face and not just the underside of your chin.

HAVE A GOOD LIGHT ON YOUR FACE.

You will become an empty silhouette if you stand in front of a window and the child has to look into a bright light. He will not be able to use lipreading clues.





STAND STILL WHEN YOU TALK.

Then the child won't have to lipread a moving blur.

HAVE THE CHILD'S ATTENTION BEFORE YOU SPEAK.

It helps to say the child's name or touch the child's hand or shoulder. Otherwise, the child may miss the first words of your sentence.

RESOURCES

Parent Groups

International Association Parents of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910

Nebraskans Interested in the Deaf
12954 Harney Street
Omaha, Nebraska 68154

RECOMMENDED READING

Journals

American Annals of the Deaf
5034 Wisconsin Avenue, N.W.
Washington D.C. 20007

The Volta Review
1537 35th Street, N.W.
Washington D.C. 20007

Books

Correspondence Course for Parents of Little Deaf People
John Tracy Clinic
1806 West Adam Boulevard
Los Angeles, California 90007

Mindel, Eugene D. and Vernon McCoy
They Grow in Silence: The Deaf Child and His Family
Maryland: National Association for the Deaf, 1971.

Myklebust, Helmer R.
Your Deaf Child (A Guide for Parents)
Springfield, Illinois: Charles C. Thomas, 1950.

Pamphlet

French, Sophie, "To Parents of Young Deaf Children: Some Suggestions for Management." Reprint #907 Alexander Graham Bell Association for the Deaf, Inc. The Volta Review, April, 1968.

Chapter 12

GIVING A HEAD START TO PARENTS OF CHILDREN WITH ORTHOPEDIC DISABILITIES

Richard Galusha

The first question after, "Is it a boy or a girl?" is usually, "Is the baby all right?" Parents who find themselves with a physically disabled child are usually in a state of shock, disbelief, and despair. They may pass through the stages of fear, shame, guilt, and rejection on the way to learning to accept their child's limitations.

In an ideal situation, parents are immediately referred to a social worker, who counsels them through the stages mentioned above and assists them in finding resources for their child. Unfortunately, counseling is not always available, or it may not be acceptable to the parents, and it is left up to teachers or administrators when the child enters an educational setting, such as Head Start. By this time, the child and his parents have often accumulated many frustrations and anxieties.

It is recognized that most teachers and administrators are not trained to counsel adults. There are ways, however, that educators can work with parents toward the goal of developing the orthopedically disabled child toward his full potential, and perhaps prevent him from becoming a physically handicapped child.

Understanding the Difference

"Disability" refers to a physical or mental impairment. A "handicap" is the result of the effects of that disability. Some disabilities are relatively mild...a slight hearing loss or moderate visual problem, for examples. A hearing aid or glasses allow normal functioning, so that no handicap results from the disability. We might say that a person is handicapped only to the extent that a disability interferes with the accomplishment of particular goals.

Most of us know of physically disabled persons...some with quite severe disabilities...who have achieved a great deal. "They don't *seem* handicapped," we're likely to say. In talking with such persons about their achievements, we are almost sure to hear something like this: "My parents treated me just like my brothers and sister," or "They didn't stop me from trying anything I thought I could do, unless it involved a foolish risk." It emerges that these disabled high-achievers were not overprotected, were provided with an education, and were encouraged by parents, siblings, teachers and others to be as independent as possible. In counseling parents of physically disabled children, it is important to help them understand how their own attitudes toward the child affect the degree to which he is or will be handicapped.

Counseling Approaches

When offering counseling to parents, there are several points to keep in mind. First, don't start a relationship you would not want to continue. Define, with the parents, your common goal as it relates to their child. Make it clear that you cannot solve problems for them, but that you are willing to listen and try to help them resolve the problems for themselves.

Always take time to listen, regardless of pressures.

Be honest with parents, no matter how difficult. You must be open minded and sometimes accept facts and situations that are not part of your experience or formal learning, without making hasty judgments.

When you're wrong, admit it without becoming defensive about it:

Answering Parents' Concerns

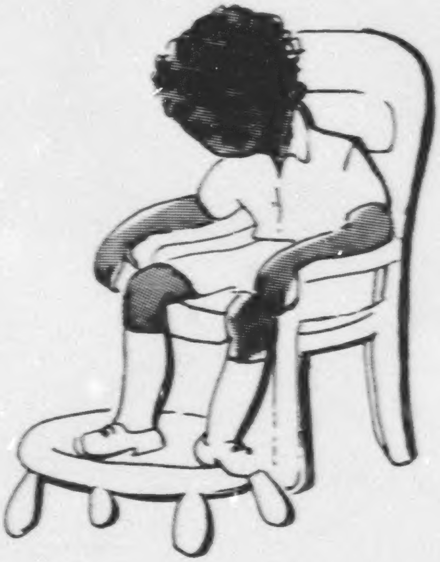
Parents may ask you, "What are my child's chances of being normal?" or "How close to normal will he be when he grows up?" You probably cannot begin to give an unqualified answer to such questions, but there are ways to discuss them. It is important to explain the difference between *handicapped* and *disabled*, as mentioned earlier. Although each child is different, with unique capabilities, you can talk generally about ways parents can build on the child's strengths to foster independence.

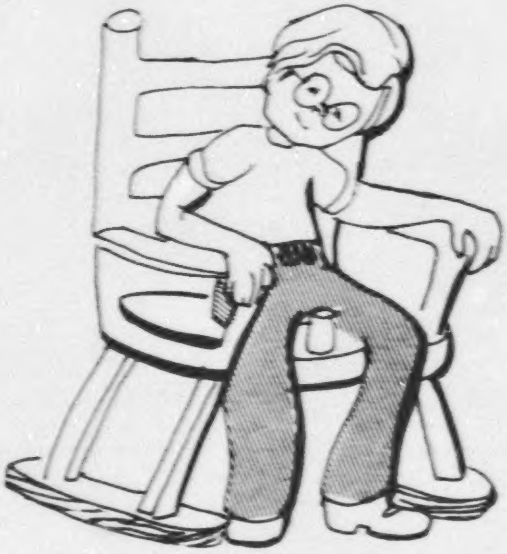
Put parents in touch with parent organizations they might join, or introduce them to parents who face problems similar to theirs. This allows them to exchange information and, equally important, to feel that they are not alone. If possible, show them children with similar problems. Make them aware of people with other problems, and show them what others have been able to accomplish in spite of their disabilities.

It may become apparent that for one reason or another, the child isn't getting the medical and/or therapeutic care which he needs. Parents may lack financial resources, or simply not be aware of what is available. You may be able to refer parents to agencies and resources which provide the needed services. They may need some help in getting into such programs. Point out the importance of working cooperatively with all agencies or organizations for the development of the child.

It is important that you understand the child's disability and his particular strengths and limitations. Familiarize yourself with the facts. If possible, talk with the physician and other professionals who may be seeing the child. You will no doubt already have made some adaptations of classroom equipment to accommodate the disabled child. Talk about these with the parents, and discuss modifications that might be made in the home environment. Some of these might include:

- Wheelchair ramps;
- Nonskid floor coverings for children on crutches or with poor balance.
- Masking tape or sandpaper on the soles of shoes to make slipping less likely;
- Footstools to help children maintain seated balance;
- Low step-platforms in front of sink, countertops, etc.
- Abduction blocks on chairs to keep child from sliding off;
- Safety straps to position child in a chair.





As you work with parents, encourage them to examine their attitude toward their disabled child. Help them look at their degree of protectiveness...are they so protective that they make the child feel helpless, or so much the opposite that he feels unsafe and has frequent accidents? Try to point out that though it is often faster to do something for the child than to take time to teach him to help himself, they do the child a disservice by not giving him the opportunity to take some responsibility. Overprotection is as bad as neglect. You might remind them that they will not always be there to help.

Finally, share anecdotes about the child's progress with the parents frequently. The attitude you project toward the child may influence that of the parents; make sure it is a positive one.

Orthopedic Disabilities

There are many different causes of orthopedic disabilities which may range from congenital malformations to automobile accidents. Three of the most often seen are cerebral palsy, spina bifida, and muscular dystrophy.

Cerebral Palsy is caused by damage to the parts of the brain which control and coordinate muscular action. Most often, the damage occurs before or during birth.

There are three main types of cerebral palsy. The *spastic* child moves stiffly and with difficulty; the *athetoid* has involuntary, uncontrolled movements; and the *ataxic* child experiences disturbance in the sense of balance and depth perception.

The range of severity is wide. Cerebral palsy can cause conditions ranging from a slightly perceptible awkwardness of gait to confinement to a wheelchair. Resulting disabilities may include impaired vision, hearing, speech, mobility, learning ability, or intelligence. Seizures and psychological and behavioral problems also may be present.

A number of factors may cause cerebral palsy. Defective development of brain cells before birth, physical injury or infectious disease may result in cerebral palsy. Poor health of the mother or certain virus infections in early pregnancy, Rh or A-B-O blood type incompatability between parents, lack of oxygen to the developing brain and premature birth may also be contributing factors.

With rare exceptions, the diagnosis of cerebral palsy will have been made before the child reaches preschool. As a baby the child may have been tense or irritable, experiencing difficulty with sucking. Abnormally slow development of muscular control and coordination also may be early signs of the condition.

There is no known cure for cerebral palsy. Early diagnosis and intervention are important if handicaps are to be minimized. Effective treatment often requires physical, occupational, speech and hearing therapy. Orthopedic surgery is indicated in some cases, and braces might be prescribed to prevent or correct deformity.

Teachers of preschoolers with cerebral palsy need to understand the degree of severity of the child's case, and to be informed of treatment which the child has undergone or is receiving at the time. If a physical and/or occupational therapist are seeing the child, they can be a valuable resource for the teacher in learning to adapt classroom activities to the child's strengths and limitations.

While many parents are extremely knowledgeable about their child's condition, others may not be fully aware of the information and community resources that are available to them. Staff should seek all available non-technical literature, both for their own use and to share with parents.

Look upon parents as resources as well. Though they may not have a great deal of technical knowledge about cerebral palsy, they *do* know their child... his likes and dislikes, what he does well, etc. Draw upon this knowledge and give parents all the credit they deserve for the positive things they do for their disabled child. Explain the objectives of the learning experiences you provide for the child, and encourage them to continue with them at home.

Spina Bifida, while occurring less often than cerebral palsy, is the commonest abnormality of the spine. Like cerebral palsy, it may range from mild to very severe.

When a child has spina bifida, it means that some of the vertabrae which normally cover and protect the spinal cord have failed to develop fully. The defect may occur anywhere on the spine, but most often is found on the lower part, the last of the vertebral column to close.

No symptoms may be noticed in its mildest form. At the other extreme, the spinal cord forms a flat plate (rather than the normal tube) and protrudes from the surface of the body, covered not with a backbone, but only with the membranes which normally cover the spinal cord.

A further difficulty occurring with many severely involved children is hydrocephalus, the abnormally rapid and excessive enlargement of the head due to the collection of fluids. Surgical procedures to cover the spinal protrusion and to prevent enlargement of the head may be necessary.

Whatever the degree of severity, the nerve fibers which carry impulses to and from the lower portion of the body will be affected. Some children have only a slight limp as a result, while others may be confined to wheelchairs and be without control of bowel and bladder functions. Some experience a lack of sensitivity to heat, cold, or pressure in the lower part of the body. If hydrocephalus is present, intelligence is very often affected. Another complication frequently observed is visual abnormalities.

The reduced mobility of children with the condition, along with bowel and bladder problems, appears to have an effect on their development of social skills. However, some researchers speculate that overprotectiveness on the part of parents and siblings may also contribute to this social immaturity.

As with other physically disabling conditions, the teacher must have a good understanding of how the condition affects the individual child if he or she is to work effectively with parents in the child's best interests.

Muscular Dystrophy includes a group of genetically determined disorders of the muscles. Diagnosis may not be made until the preschool years or, in some forms, adulthood.

If a preschool child has this condition, it would likely be the Duchenne type. It is inherited as a sex-linked recessive trait, afflicting only males with females as carriers. Progression is relentless and rapid, and life expectancy generally doesn't exceed 20 years. Children with this type of muscular dystrophy usually regress from walking to braces to crutches to wheelchair. There is no cure, but treatment is available to make life more bearable. Active exercises help to prevent the atrophy of muscles that are not involved. Diet must be watched to prevent obesity resulting from inactivity.

A child with muscular dystrophy in a Head Start program will most likely be in the very early stages of the condition, and may still be able to be quite active.

The parents of this child will undoubtedly be in the early stages of shocked reaction to the diagnosis. The relentless progression and grim prognosis of the disorder makes acceptance doubly hard for them. Teachers need to be especially sensitive and supportive to parents facing this situation. It will be difficult to really identify with the way they feel; however, you can listen, and you can share your pleasure in the child's accomplishments and the friendship you have with him. If possible, help the parents realize that, although they can do nothing to halt the progressive worsening of their child's physical condition, their attitude and treatment of the child will have a profound effect upon his morale and the way he eventually comes to accept the long-term implications of his condition.

RESOURCES

Arthrogryposis Association, Inc.
106 Herkemir Street
North Bellmore, New York

Human Growth Foundation
307 5th Avenue
New York, New York 10016

Muscular Dystrophy Association of America
1790 Broadway
New York, New York 10019

National Easter Seal Society
2023 West Ogden Avenue
Chicago, Illinois 60612

National Foundation, March of Dimes
1275 Mamaroneck Avenue
P. O. Box 2000
White Plains, New York 10602

Spina Bifida Association of America
P. O. Box 5568
Madison, Wisconsin 53705

United Cerebral Palsy Association
66 East 34th Street
New York, New York 10016

Nebraska

Arthritis Foundation of Nebraska
7764 Dodge Street
Omaha, Nebraska 68114

Easter Seal Society of Nebraska
12177 Pacific Street
Omaha, Nebraska 68154

Muscular Dystrophy Association of America
1906 North 90th Street
Omaha, Nebraska 68134

United Cerebral Palsy of Nebraska
2141 North Cotner Boulevard
Lincoln, Nebraska 68505

RECOMMENDED READING

Dorward, Barbara. *Teaching Aids and Toys for Handicapped Children.* Washington D.C.: The Council for Exceptional Children, 1960. ($1.75)

Finnie, Nancie. *Handling the Young Cerebral Palsied Child at Home.* New York: E.P. Dutton and Co., 1968. ($3.50)

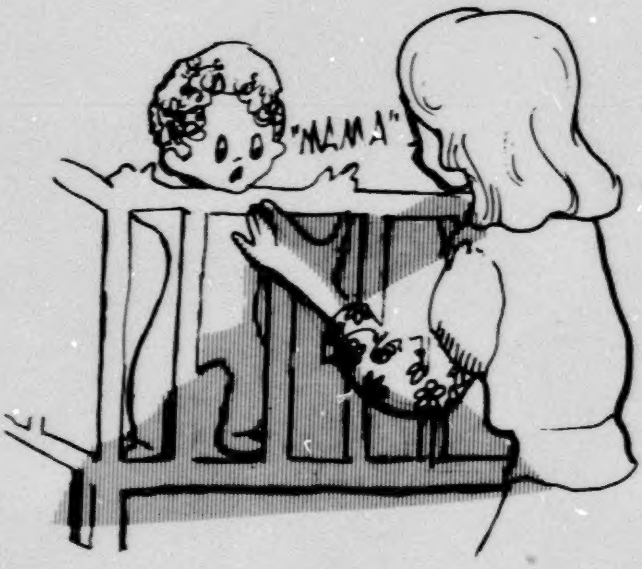
Please Help Us Help Ourselves. United Cerebral Palsy Association of Central Indiana, Inc., 615 Alabama Street, Indianapolis, Indiana 46204. ($2.00)

Feeding the Child with a Handicap. Health Services and Mental Health Administration, Maternal and Child Health Service, Washington D.C.: U. S. Government Printing Office, 1967. ($ .30)

Chapter 13

GIVING A HEAD START TO PARENTS OF CHILDREN WITH SPEECH AND LANGUAGE DISORDERS

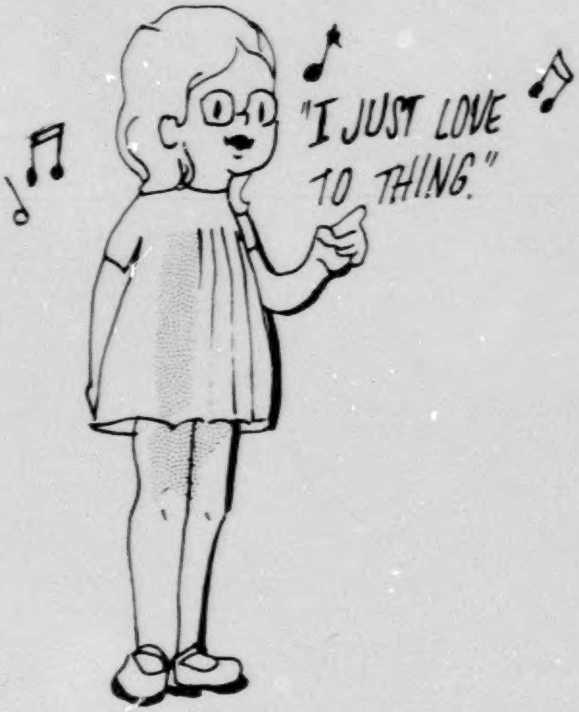
Edwin Leach



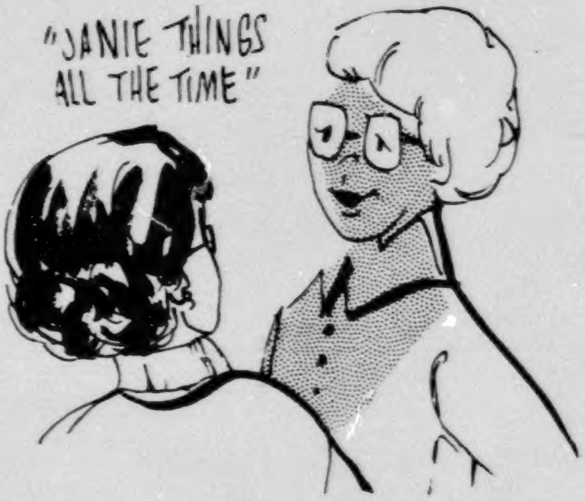
A child's speech development in the early years is probably the most noticed aspect of growth in spite of the child's other achievements during those years. Parents usually take note of the first words; when the child says "Mommy" or "Daddy," and when the first sentence is formed. Some parents take great delight in these steps forward and may prompt the child endlessly in an effort to hurry the process of acquisition. Parents, most of the time, make accurate appraisals of their child's developmental accomplishments. As a consequence, they provide appropriate guidance for their children.

However, when a child does not develop speech and language within normal limits, the parents may be confused by the problem and, in seeking help, turn to you. In an effort to provide some guidelines for this extremely important position as a counselor, the following recommendations are made. Naturally, it is impossible to anticipate all of the questions which may arise or to provide clear sensible answers. Situations will occur for which any answer may seem inappropriate. However, the following suggestions are given in response to frequently asked questions. A study of these recommendations will help in other situations as well.

Does the child have a speech and language problem?


"I JUST LOVE TO THING."

This, of course, is the first question to be answered, because all counseling recommendations will be outgrowths of this decision. Explore why the parents or others feel the child does or does not have a problem. Is their estimate reasonable? Is the concern generated by neighbors and friends? Comparatively, does the child's speech and language differ significantly from other children his own age? Is the child's speech and language development different from that of other children in the family? Does the child demonstrate very good speech and language...but only when "he wants to?" Has the child made significant progress in recent months or is he still plodding along now much as he always has? Do other children understand the child quite well? How long have the parents been concerned? Questions like these should generate information on which some decisions may be made.


"JANIE THINGS ALL THE TIME"

The child with a speech and language problem develops communication skills very slowly. At three or four years of age, his communication may be more like an 18 month old child, or even younger. These children often behave as if they didn't understand you, or their understanding is inconsistent and possibly erratic...sometimes they understand and sometimes they don't. Many speech and language deficient children will play with or among other children, but make few attempts at verbal communication. It is as if they have tried and tried, but having met failure so often, they no longer attempt it. More than likely, they will rely upon physical encounters or direct manipulation of toys, etc. to express what they wish. They may be described as "loners" in the classroom. Frequently, these children are inattentive or direct their attention only fleetingly on specific events or items. One often hears the term "short attention span" or "hyperactivity" applied to them.

A frequently encountered problem is the parent who becomes overly concerned because a child cannot pronounce "s" or "r" sounds correctly even though the child is only 3½ or 4 years old. Parents who bring this concern to you may be reacting to friends who cannot understand the child, or perhaps may be reflecting their own ambitions for the child. Whatever the reason, they usually are not aware that many perfectly normal children may be 8 years old before these language sound elements are pronounced correctly. Also, in the process of acquiring these sounds, the child may be very erratic in his accomplishments. He may go for a year or two with virtually no progress and then move ahead very rapidly in a three month time period and make up for lost time. At times, some children may even regress briefly, especially when they are concentrating on mastering a new skill. Of course, there are some exceptions when a 3 or 4 year old may need help for his articulation. However, this is an unusual circumstance and you will not go wrong by advising the parents to be patient. It is not unusual for these sounds to be difficult for a four year old to make. The important characteristic at this age is language usage, not how clearly the child talks.

Many children with significant speech and language handicaps will evidence other problems as well. There may be behavior problems which seriously interfere with classroom interactions among the children or between child and adult. Associated physical problems such as visual and/or auditory impairments may be suspected. Dental problems can influence selected aspects of the child's speech and reduced intellectual capability can affect a variety of the child's skills. These related problems, because they do often co-occur along with speech and language problems, will help to identify the child.

The type of problem, the severity of the problem and the nature of remedial services are decisions which should not concern you. The central question facing you is, does the child have a problem? In the event you are undecided on this question ask for a professional opinion from a speech pathologist. It is always better to err in the direction of considering a child to have a problem and then later find out he did not, than to do nothing for the child who has a problem.

Where to Go for Help?

Locating available services and qualified speech pathologists can be confusing. These services and the qualifications of individuals who deliver them will vary considerably depending upon your geographical location. However, there are some simple guidelines. Your role should be one of providing accurate, reliable information on which the parents can act.

First of all, many professional people will react much more favorably to your concerns and the parents' concerns if you describe the problem well without telling them what is wrong and what should be done. For example, don't call the child's physician and give him vague accounts of the child's behavior in the classroom followed by a question, "Do you think he is an epileptic?" or "Do you think he is retarded?" A much more positive approach is to describe specific problem behaviors, how they interfere with your interactions with the child, and then simply ask for recommendations on what might be done. This approach gives the professional appropriate information and leaves the conclusions or diagnosing up to him or her.

Secondly, seek out different professions and different people for recommendations concerning any single problem. Don't expect the family physician to know much about speech and language problems, he won't. Don't expect the psychologist to know much about dental problems, he won't. And don't expect the speech pathologist to know much about drug influences on behavior, he won't. However, by discussing a child's particular problem with more than a single source, you may gain a useful perspective on the problem in addition to gathering several possible alternatives for a solution. Caution the parents not to depend heavily upon a single source for guidance, since jumping to solutions for relatively chronic problems seldom makes much sense. Chronic problems, unlike crisis decisions, usually necessitate much more deliberation and discussion in order to reach a resolution.

Finally, your role here should be supportive to the parents in pursuing remedial help. You are the one experiencing the child's problem in the classroom. The parents are the ones experiencing the child's problem at home. Together you must continue to search for the services which will eliminate or minimize the problem. If you see your role in this fashion, you can best serve the needs of the parents and the child and you can act as a reliable informant about the success or failure of any remedial efforts.

What Can Be Done at Home

Whether a child has a problem or not, there are many activities which may be carried on at home to support improved speech and language development. Generally speaking, children's television shows which involve them on an interactive basis are good for them. Shows like Sesame Street invite the viewer to count, answer questions, name letters of the alphabet, etc. In contrast, shows like cartoons seldom involve the child and are not likely to provide much more than simple entertainment.

Like the TV shows mentioned above, many children's records involve the child either through sing-along activities or through questioning and interaction. This type of activity forces the child to be attentive, to retain certain visual and/or auditory information, and to recall them later. All of these activities are basic to the development of good communication and will have a beneficial effect on the child's speech and language.

Reading to a child is one of the most important adult - child interactions in early childhood development. It incorporates the attention retention and recall features mentioned earlier

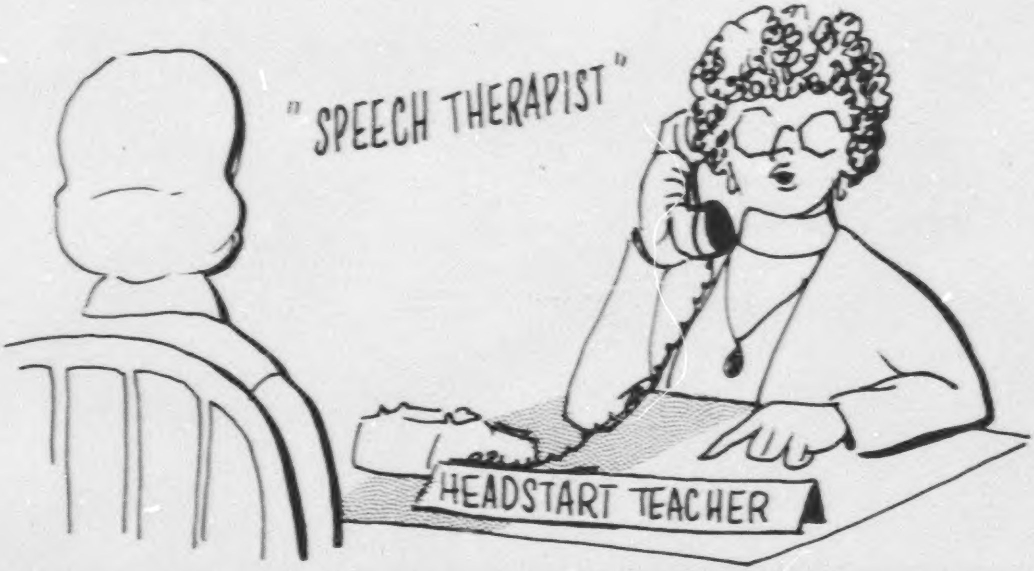
since nearly all adults routinely involve the child during the process of reading by asking questions about the story, discussing the pictures, etc. The personal interaction with the adult provides the child with undivided attention. A few minutes of reading is extremely valuable to the child and should be at most a daily activity.

Another important home activity is the inclusion of each child, regardless of his communication capability, within the family's interactions. Even though a child may have very limited communication ability, it is important to talk to him and involve him at his level of communications. Most mothers will talk constantly to infants even though the child may be only two or three months of age, capable of a few vowel-like sounds coupled with smiling or crying. Even though a child may have a limited ability to respond, much like a three month old infant, he must be included in the family conversations and not excluded simply because of his limitations. It may be much harder to interact with a relatively non-verbal four year old child than a four month old child, but he needs the speech patterns as models if he is to progress.

Speech and language development is the result of children and adults conversing with each other. The essential features of these "conversations" are not unusual. A child's language acquisition is the result of simple activities, employed by most parents in an almost intuitive fashion. The infant or young child is amazingly flexible in his adaptability to our sometimes fumbling efforts. If parents follow these common yet effective home activities of reading, conversing, discussing, questioning, etc., most children will acquire speech and language in a normal fashion.

What Should Not Be Done?

A frequent concern of parents is what "caused the problem." Some parents are very involved with the cause and may over-emphasize this aspect. Don't let this dominate the discussion about a child. Causal factors will likely never be determined even with many professional opinions. The important consideration for the child is what can be done to solve or minimize the problem. Focus the parents' concerns on remediation. Causal factors, even when known, are seldom alterable.



Sometimes parents have been told, "He will outgrow it," by well-intentioned friends or even professional people. As a consequence, you may find your concerns ignored or at least not well received. Don't let this deter you from trying to do something about it. Quite often, communication problems are not apparent until the child is placed in a situation like a classroom. Having to communicate with others outside the home and having to pay attention to classroom rules often triggers the first notice of a problem. While the parents may have noted certain aspects of the child's behavior, they may not have realized the significance of it. Invite the parents to observe their child in the classroom. Bring in others to advise you and/or the parents. Don't let "outgrow it" advice prevent you from facing up to what may be a real problem.

Finally, don't depend upon others for a follow-through of the problem. You may have to assume this important role. When alerted to the fact that their child has a problem, some parents may accept it readily, but others may leave this to whomever will assume the responsibility. This role may require considerable patience and thoughtfulness on your part. You may receive little thanks beyond seeing that a child has been placed properly and is receiving appropriate services.

RESOURCES

Meyer Children's Rehabilitation Institute
Department of Speech and Language
444 South 44th Street
Omaha, Nebraska 68131

RECOMMENDED READING

Hansen, Susan. *Getting a Head Start on Speech and Language Problems*. Omaha: University of Nebraska Medical Center, 1975. ($1.25)

Johnson, Wendell, et al. (Eds). "Speech Disorders and Remedial Speech Services" (Chapter 1). *Speech Handicapped School Children*. New York Harper and Row, 1967 (3rd Edition).

Lavatelli, et al. (Eds). "A Tutorial Language Program for Disadvantaged Infants" (Chapter 4). *Language Training in Early Childhood Education*. Urbana, Ill.: University of Illinois Press, 1972.

Chapter 14

GIVING A HEAD START TO PARENTS OF CHILDREN WITH HEALTH IMPAIRMENTS

Paul Pearson, M.D.

Introduction

The conditions discussed in this chapter include life-long diseases causing differing, often progressive degrees of disability, (e.g. hemophelia, sickle cell disease) or increased risk of early death (e.g. leukemia, cystic fibrosis). Staff dealing with these children need to have some knowledge of each disease and its potential complications, and an understanding of the possible psychological reactions that may affect the children and their parents. Only by starting from this base of understanding will it be possible to sort out the probable causes of a child's behavior and take effective corrective action. The essential question at all times is, "What is causing this child's particular response?"

Do not automatically assume that a child's unusual or unwanted behavior has occurred because of the chronic illness, when in fact, the same behaviors also may occur in well children. You must attempt to decide whether the particular behavior is the normal response of the child to something unrelated to the illness, the response of a sick child to an essentially normal environment, or is secondary to emotional difficulties that the child, the parents, siblings and others are experiencing related to their understanding of the condition and its effect on their respective lives.

To do this effectively, a great deal of time, effort and sensitivity on the part of staff is required. First gather as much information as possible about the family. (What do the child and the family know about the disease and its implications? What specific instructions and advice have they been given regarding the management of the child?) Second, obtain permission to exchange information with the child's physician in order to prevent any misunderstanding concerning medical management during attendance at school. Third, strive to be as sensitive and understanding as possible about the way the child and the family are responding emotionally to their knowledge of the condition.

Each of these factors must be reassessed periodically since they will change as the child grows older, the disease progresses, and as the child and family face new demands. The attitudes of both child and family are bound to change as the child grows older and as the pattern of the disease changes over time.

It is not within the scope of this chapter to discuss the many ways in which children and their families may respond to the presence of the chronic illness in the child. However, several generalizations may be helpful.

Freeman,* writing in the Journal of Special Education points out that any chronic illness in a child may threaten emotional development if it interferes with normal activity (thus leading to frustration), if it causes parents and other adults to become overly solicitous or protective, if the child is made to feel different from others, and if it limits the social experiences of the child. (An ill child who cannot keep up is not considered the best of playmates.) These factors are particularly important, since children tend to develop their self-image from the judgment of their family and others whose opinion they value.

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*Freeman, Roger. *Journal of Special Education*, No. 5, Vol. 4., pp 389-414, and No. 3, Vol., pp. 93-99, *Rehabilitation Literature*, September 1967, Vol. 28, No. 9.

Freeman tells us that the chronically ill child rather than developing a basic trust that his needs will be met by his family, "...may sense the world as chaotic, painful, unsatisfying, or capricious."

The average child during the preschool years shows pride in bodily functions and abilities, and this provides the incentive or reward system for practicing his skills. The ill child may not have this incentive to try new activities, or the opportunity to try may be greatly reduced. This may result in a child who "won't try anything" or gives up easily.

A major cause of behavior problems in all children is a severe inconsistency between how the child is handled within the family and in situations outside the family environment. This inconsistency creates stress by making it difficult for the child to find secure and consistent ways of dealing with people. At the same time, each child, depending on his personality and interactive patterns, will react to these stresses in his own way. In other words, similar behavior problems in different children may have a variety of causes. Appropriate management requires trying to identify and then reduce the inconsistency in the child's life while helping the child develop better ways of coping with the problem.

Sickle Cell Anemia

Sickle cell (anemia) disease is an inherited abnormality of the red blood cells occurring primarily in black people. It is occasionally found in Puerto Ricans, Latin Americans and some people of Arabic ancestry. For the child to have the disease, both parents must have either the disease or the sickle cell trait. Individuals with the trait show no physical signs of the disease, although a certain number of their red blood cells will "sickle" in laboratory tests. The disease is diagnosed by laboratory tests demonstrating the presence of the abnormal hemoglobin, which causes the normally saucer shaped red blood cell to collapse under certain conditions (primarily low oxygen in the blood) into a "new moon" or sickle shape. These cells are also more fragile and break up faster than cells with normal hemoglobin, causing the characteristic anemia.

The signs and symptoms are generally related to the degree of anemia. In severe cases the child will be weak, listless and show shortness of breath with minimal amount of exercise. These children will tend to be small and thin. In severe cases, the whites of their eyes turn yellow from jaundice and there is enlargement of the liver, spleen and heart. In less severe cases under proper nutrition and care, the children may be indistinguishable in appearance and activity from the normal children.

Occasional attacks of severe pain, which may be located in the abdomen, the arms, legs or back, signal the onset of so-called "sickle cell crises." These require prompt medical attention. The attacks may be quite serious but usually clear up in five to seven days. Since these children are very susceptible to infection, the appearance of severe pain or fever requires examination by a physician.

Unfortunately, there is no specific treatment for sickle cell disease itself. Transfusions may be given if the anemia is severe. Treatment of a sickle cell crisis may require hospitalization, but whether at home or in the hospital, the physician's primary goal is to maintain the child as comfortably as possible until his symptoms clear up. Because the symptoms of severe abdominal pain, fever and high white count can mimic acute appendicitis, or other acute abdominal emergencies, often the physician's most difficult task is in making the correct diagnosis in order to avoid unnecessary surgery.

The majority of children with sickle cell disease can lead essentially normal lives with little or no restriction in activity except during those times when the disease flares up in a painful "crisis." This is particularly true of the younger child, before some of the long term complications of the chronic disease have occurred. Some of these crises may be brought on by very strenuous exercise, possibly by swimming in very cold water or by infection. Since most children learn for themselves just what they can or cannot do, it is generally felt that they should not be restricted from taking part in the normal activities at school. As with all chronic disabling conditions, those dealing with the child must make every effort to create a normal atmosphere in which the child may grow and develop with his or her own peers.

Cystic Fibrosis

Cystic fibrosis of the pancreas (usually people simply call it "cystic fibrosis") is an inherited disease in which the most prominent symptoms are chronic, progressive lung disease and an inability to properly digest some foods. The child must inherit the abnormal gene from both parents since it takes two abnormal genes to produce the disease. The parents show no signs of the illness, since each has one normal and one defective gene. The other brothers or sisters of the child may or may not have the disease, depending on whether they inherited the normal or defective gene from each of their parents. Cystic fibrosis occurs in about one out of every 1,500 white births but is quite rare among black children.

For reasons which are complex and not clearly understood, the disease ranges from quite mild in one person to quite severe in another. Although other organs may be involved in severe cases, the lungs and the pancreas are always affected. In some cases, there is also an increased tendency to develop sinusitis and a chronic runny nose. As a rule, the more severe the disease, the earlier the symptoms will appear which lead to a diagnosis. The diagnosis can be established, even in very young babies, through the presence of the symptoms and the proper laboratory tests.

The most common symptom in virtually all cases is persistent coughing, both day and night. The cough is not contagious unless the child also has a cold. He should be protected from the colds of others as it is not unusual for these children to have repeated episodes of pneumonia. As the disease progresses, the problems of chronic lung disease, infection and shortness of breath, become more and more prominent, affecting the child's appetite and the ability to play and keep up with classmates. Since there is no known treatment for the cause of the lung disease, the doctor can only treat the infections with antibiotics and use various treatments to try and clear the lungs of the thick mucous that characterizes the disease.

Digestive disturbances result from involvement of the pancreas and, like the lung disease, may be mild or quite severe. The lack of certain digestive enzymes ("juices") from the pancreas affects the digestion of fat and protein, leading to their loss in the bowel movements and causing large, foul smelling stools. The severely involved child will be small and thin. Fortunately, the digestive enzymes can be manufactured commercially and fed to the child. A well balanced diet with supplementary vitamins is usually recommended.

Because most of the symptoms and complications affecting the child with cystic fibrosis relate to the respiratory system, (chronic coughing, sinusitus, bronchitis and recurrent pneumonia) there may be a tendency to over protect the child from undue exposure to drafts, cold air, getting wet or "over heated," etc., - all commonly attributed as causing "colds." However, there is no good medical evidence that any of these factors, except perhaps in the most extreme situation, have any influence on the frequency of respiratory infections in children.

Physical activity is actually quite important in preventing the accumulation of the lung secretions that lead to infection and increasing symptoms of chronic lung disease. Active play, running and swimming (but no diving) should, in fact, be encouraged as an effective way to help raise the lung secretions. These children should have no restrictions put on their activity and, within the limits of their physical stamina, should be encouraged to take part in normal school and play activities.

Behavior problems, particularly in the Head Start or preschool age child, are more apt to be related to parental anxieties and to the fact that these children often simply do not feel well. As a rule, they will not be aware of the long term nature of their disease and its poor outlook. In dealing with behavior problems in these children, it is important to distinguish those behaviors arising because they are children, those that may be the result of the stress and anxiety associated with the disease, and those caused by not feeling well.

Childhood Diabetes Mellitus

Diabetes is a metabolic disorder involving the body's production and use of insulin. This results in a breakdown in the body's metabolism of carbohydrates (sugars and starches), causing greatly increased amounts of sugar to appear in the blood. The body gets rid of the excess blood sugar by filtering it through the kidneys; therefore, we find the diabetic making a great deal of urine in order to carry away the excess amount of sugar. The diabetic must drink large amounts of water in order to prevent dehydration from this large loss of body fluid.

Drinking large amounts of fluid and passing large amounts of urine are two early symptoms in a child who is developing diabetes mellitus. A third early symptom in children is loss of weight. If the diabetes is not recognized and treated at this point, the body, because it cannot properly use sugar, begins to use its own fat and protein, producing excess amounts of what are called ketone acids. As these accumulate in the body, they cause a loss of appetite, eventually vomiting, and finally, if not treated, coma and death.

Diabetes in children usually has an abrupt or rapid onset. The diagnosis needs to be made and treatment started soon after the early symptoms appear (within two to three weeks) in order to prevent the development of dehydration, coma and possibly death.

Unlike the adult form of diabetes, virtually all childhood diabetics must take insulin. There may be a period of several months after the disease is first diagnosed and treated when the child needs very little insulin, but after that they begin to need increasing amounts. The insulin must be given by injection and, depending on the type used, may be given one or more times each day.

Diet control in children will vary with the physician and the particular case. Because it is difficult to keep children on a strict diet, most physicians advise letting diabetic children select their own diet, but limiting excessive intake of candy, ice cream and pop.

There are several complications of childhood diabetes with which anyone working with these children needs to be familiar. The most common is the so-called *insulin reaction* resulting from very low blood sugar in the presence of too much insulin. Because of the danger of the reaction progressing to a severe stage such as convulsions and coma, it is important to recognize the early signs and symptoms. These usually consist of hunger, anxiety, sweating and faintness. The child often gives the first evidence by being unusually irritable rather than complaining of hunger or anxiety.

Prompt feeding with sweetened juices or fluids such as orange juice should quickly relieve these symptoms by restoring the blood sugar.

Any acute infection, even a bad cold, in a diabetic child should be treated as serious, requiring prompt referral to a physician. This is especially true where the infection causes vomiting or diarrhea.

Emotional aspects of diabetes are also important. In the preschool child, most of the emotional impact will relate specifically to the pain of the insulin shots. At this age, they have difficulty understanding the need for shots or for regulation of their diet; they are unaware of the lifelong implications of the disease. Any general emotional disorder is probably a reflection of their parents' reaction to the diagnosis. In this regard, it is important for the teachers to handle the child in the same manner as they do their classmates. As a rule, no restriction in activity or limitation in performance should be expected for the child with diabetes.

The nutrition coordinator should visit with the parents and the doctor about the type, quantity and time that meals and snacks should be served. Treats that are on the child's diet list should be planned for parties and special occasions.

Heart Disease

Because of the wide variety of conditions involving the heart and the equally wide range of their effects on the health and activities of the child, only the most general kinds of statements can be made here. Heart disease in children can best be thought of in terms of either acquired diseases, such as rheumatic fever, and congenital heart disease resulting from so-called birth defects.

Among the acquired diseases, heart disease due to rheumatic fever is the most common and the one teachers are most apt to see in the classroom. The child would not be in school during the acute phase of the illness and, therefore, once returned to the classroom would be on a regimen described by the attending physician. Most children who have had acute rheumatic fever will be taking medication on a regular basis.

Children born with heart defects are generally categorized as either the cyanotic, the so-called "blue baby," or non-cyanotic type. The cyanotic child is born with a defect which permits the dark blood from the veins to mix with the red, oxygen rich blood coming from the lungs. While generally speaking, the child with cyanotic heart disease has a much more disabling condition, there are very serious non-cyanotic forms of congenital heart disease as well.

From the standpoint of staff dealing with a young child with reported heart disease, whether acquired or congenital, they must obtain quite specific instructions from the child's physician regarding limits of activity. A good general rule which most physicians would support is that the child with heart disease is his own best judge of how much activity he or she can safely tolerate. Most children with heart disease will stop to rest when they reach their physical limits. Children with mild forms of congenital heart disease should be able to participate fully in all activities, including competitive sports. Physicians no longer require the restrictions formerly imposed for many of these children.

The teacher can help by careful observation of the child's activity tolerance, encouraging or providing opportunities for rest periods. Avoid placing the child in unduly strenuous or competitive situations. They should play for enjoyment but not push until totally exhausted.

It is equally important, that staff avoid an overly protective or solicitious approach to the child. The danger of psychological damage... making a "cardiac cripple" out of a child...is probably greater than the potential for physical damage from self regulated activity. As with almost all chronic conditions, the child needs to be allowed to live as nearly normal a life as possible.

Hemophilia

Hemophilia is an inherited disorder of the blood clotting mechanism resulting in spontaneous bleeding into various parts of the body from time to time, and prolonged bleeding any time there is a bruise or cut. The inheritance is called "sex-linked" in that the most common forms of the disease occur only in males. While the specific defect in the clotting mechanism of the various forms of the disease have been identified and are fairly well understood, the only available treatment is through periodic replacement with whole blood, plasma or specific fractions of the blood containing the missing clotting ingredients. The condition is lifelong in that no cure is now available.

The bleeding tendency is present from birth, and not only may ordinary falls and tumbles produce large bruises or prolonged bleeding, but spontaneous hemorrhages occurring into various body organs may have serious consequences. A common site for such bleeding is into major joints, such as the knees. In the acute episode, this produces a swollen, very painful joint. Repeated bleeding episodes into the same joint eventually produce arthritic changes and permanent stiffening of the joint.

Despite these problems, children with hemophilia need the opportunity to take part in regular Head Start school programs. They must, of course, avoid contact sports. In the event of a fall or injury, local measures, such as application of direct pressure to a cut, immobilization of a joint, and application of an icebag or cold compress should be initiated promptly until the child can be seen by the physician. Any evidence of fresh bleeding, and pain or swelling in a joint or any part of the body requires prompt referral to a physician.

Tooth extraction is a major procedure in these children, therefore preventive measures should include good dental hygiene. Physical therapy is used to prevent loss of motion in joints that have been involved in bleeding.

The behavior problems in these children are most apt to relate to their need for frequent visits to the physician's office or hospital for intravenous therapy, and those arising from their restriction from taking part in the usual rough and tumble play common to all children. As with most children with chronic disabilities, they soon learn to protect themselves. Teachers and staff need to exercise their ingenuity to provide outlets for their youthful energy through activities which will not physically endanger them.

Leukemia

Leukemia is a disorder of the blood forming system of the body in which there is a disorderly increase in the white blood cells. These white blood cells, generally young or "primitive" types, enter the circulation in large numbers and invade many of the body organs.

In young children it is almost always rapid in onset. Leukemic cells replace normal blood cells, invading and enlarging such organs as the liver and spleen within a few weeks. Without treatment, death occurs within three to six months as a general rule. The cause, as with most types of malignancies, is unknown. The disease, however, is not contagious. It occurs most often in the first five years of life and in city children. It is less common in rural children and in Negroes.

It is an "on again, off again" disease in which symptoms suddenly appear and then disappear completely (a complete disappearance of symptoms is called a complete remission) usually as a result of treatment, although a remission may also occur spontaneously. The acute symptoms can mimic almost any infectious disease with fever, nausea and vomiting and a variety of aches and pains. More commonly, the first signs are those associated with severe anemia and easy bruising.

Although leukemia is still considered almost invariably fatal, specific treatment is now available which can maintain the child in good health or complete remission for periods of many months and even years. Children who are surviving four to ten years after onset of symptoms are now being reported. During periods of complete remission, the child can enjoy normal, unrestricted activity. It is unlikely that a child undergoing therapy would be found in a day care or nursery school setting.

Perhaps the most important requirement for the teacher or other staff who deal with the child during remission from leukemia is to maintain open lines of communication with the parents and the child. The staff's management of the child, at least in relationship to his or her disease, must be based on what the child, the siblings and the classmates have or have not been told about the nature of the disease. For example, are the parents attempting to shield the child from any knowledge about the serious, long term outlook, or have they decided to deal with it openly and in a positive manner.

It is generally accepted that most preschool age children should not be told too much about their potentially fatal disease, because the young child might become quite confused. At the same time, both parents and teachers should be extremely sensitive to just what the child knows or senses. One study found that leukemic children above the age of four were aware of the serious nature of their illness and even anticipated death, despite their parents' efforts to shield them.* Younger children were more concerned about being hurt or separated from their parents. For an adult-like concept of death takes place, as a rule, around the age of eight-to ten years.

While staff have little choice but to follow the parents' wishes, the best way to protect the child from the shock of accidental disclosure and teasing from classmates is to discuss the illness with the child and siblings in an age appropriate way. When this has been done, the children appear to benefit and show less tendency to depression and withdrawal. Even in, or perhaps most particularly in, such life-threatening situations, the child needs an environment in which he feels he can ask any question safely and receive an honest reply.

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*Benger, et al. 1969, see Freeman, *Journal of Special Education*, Volume 5, No. 4.

RESOURCES

National

American Diabetes Association
18 East 48th Street
New York, New York 10017

American Heart Association
44 East 23rd Street
New York, New York 10010

Foundation for Research and
Education in Sickle Cell Disease
421-431 West 120th Street
New York, New York 10027

Leukemia Society of America
211 East 43rd Street
New York, New York 10017

National Cystic Fibrosis Research
Foundation
3379 Peachtree Road, N.E.
Atlanta, Georgia 30326

National Hemophilia Foundation
25 West 39th Street
New York, New York 10018

National Kidney Foundation
116 East 17th Street
New York, New York 10016

Nebraska

American Diabetes Association
of Nebraska
921 Dorcas
Omaha, Nebraska

Nebraska Heart Association
3624 Farnam Street
Omaha, Nebraska

American Cancer Society
6910 Pacific Street
Omaha, Nebraska

Nebraska Cystic Fibrosis
8401 Dodge Street
Omaha, Nebraska 68114

Chapter 15

GIVING A HEAD START TO PARENTS OF CHILDREN WITH ASTHMA

Tom Fashingbauer

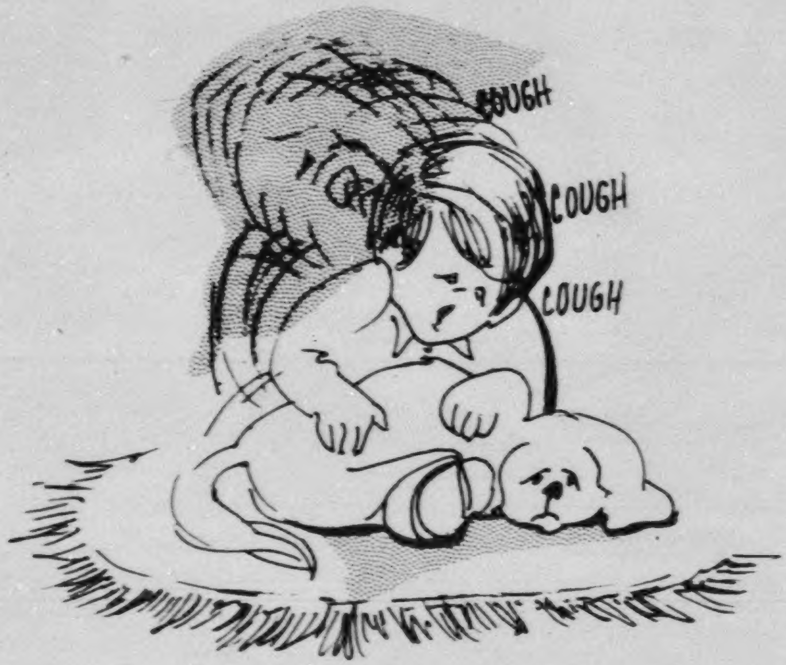
Asthma affects approximately 3 per cent of the population; among children between the ages of 1 and 5, the incidence goes up to 5 per cent. Before age 10, roughly twice as many boys than girls are affected, though the ratio appears more equal in adulthood. Boys also tend to have more severe cases of the disease. Regardless of sex, however, asthma is a condition which often fosters fear, guilt and anxiety...fear of not regaining one's breath or of not being able to live a normal life; guilt on the part of the parents for having passed the condition to the child; and the anxiety of not knowing when the next attack will occur.

Understanding Asthma

Asthma is characterized by recurrent attacks of wheezing, shortness of breath, and coughing due to spasmodic contraction of the bronchi (bronchial spasm). Though the lungs are affected, asthma is actually a disease of the air passages, or bronchial tubes.

The term "asthma attack" can mean different things to different families. It may be mild and continuous--a sort of constant wheezing--or it may be sudden and severe. An acute attack can last a few minutes, a few days, or even weeks. It respects no particular season or time of day, though the incidence is somewhat higher in the evening.

Causes triggering the condition can be grouped into allergic and non-allergic factors. The allergic factors or allergens include substances such as pollen (weeds, grass, trees), animal dander, dust (household dust, dust found in sleeping or tumbling mattresses), molds, drugs, foods, etc. In a



particular child, one or more substances can consistently produce an attack. To avoid confusion, it should be remembered that children with asthma almost always have allergies which usually cause asthma attacks. However, all children with allergies do not have asthma.

The non-allergic factors which can set off an attack include such things as infections (colds), air pollution (cigarette smoke), over-exertion caused by running or over-playing, changes or extremes in temperature or humidity, or high emotional state (anxiety, fear, strain and even joy). Unfortunately, the non-allergic factors are most difficult to control and probably cause the majority of attacks. It is not clear what causes the disease itself; however, it is known that when an attack occurs, three conditions exist:

- the muscles surrounding the bronchial tubes go into a spasm;
- the inner mucous membrane becomes swollen; and,
- thick mucus is secreted.

The result is a rasping or wheezing sound as air tries to pass through the restricted air passage. A person having a severe attack feels as if he is choking. He cannot get enough air and he cannot breathe it out afterwards. Usually he coughs a great deal and spits up white mucus. While trying to get air, a child is usually most comfortable sitting up or standing. He may perspire and when air is insufficient, he may turn slightly blue in color. His shoulders frequently slump forward and after a number of years struggling for air, poor posture (rounded shoulders and barrel chest) can result.

What To Do In Case of an Asthma Attack

In an attack situation, a teacher or parent should stay calm and try to help the child relax. Remaining calm and giving the child support and a feeling of confidence, is probably one of the most important things anyone can do once an attack is in process. As soon as a child recognizes an attack is coming on, it is important that he relax and breath deeply (diaphragmatic breathing, if possible). If caught at an early stage, it is sometimes possible to prevent or lessen the severity of the attack. Most children can recognize the onset of an attack by a scratchy throat, or tickling in the mouth, or an itching body. A child with asthma often carries prescribed medications (do not encourage commercial nebulizers--they could cause more harm than good) which he can take when having trouble. If the condition persists and appears to be getting more severe--that is, if the wheezing gets louder and there appears to be more difficulty breathing -- it may be necessary to inform the parents, and hospitalization may be warranted.

Treatment of asthma is important; reversal of the swelling, secretions and bronchial spasms is critical. In most cases, when the attack is over, no lasting or harmful physical affects remain. Optimal management of the child with asthma may be difficult because of the multiple factors involved. A comprehensive treatment plan includes a combination of avoidance of the known aggravating factors, allergen injection therapy, medications and counseling.

Social and Emotional Overtones

All chronic diseases have emotional and psycho-social overtones. How well a child learns to adjust to his condition determines whether these overtones will have a negative effect. Adjustment is a learned process in which the parents, teachers and peers participate. It is difficult for a child to think of himself as a full, normal individual if from his early years he is isolated and treated as if he were different from other children. Often, the restrictions imposed upon the child by others (or even by himself) are more limiting than the disease. Well-intending people may try to protect the child by sheltering him from all physical activity and exertion. School personnel usually know little about the disease and would rather have the child sit on the sidelines than risk an attack. The child himself tends to impose restrictions because of fear of failure or ridicule. This often leads to a lack of self-confidence, and the child becomes unwilling to risk himself and participate. For this reason, a positive, supportive and encouraging attitude from adults and peers is essential if the child is to learn to help himself. He should not be made to feel different from others. His limitations may occasionally lead to poor performance and frustration; but this type of struggle, together with learning to control his condition rather than being controlled by it, can lead to growth, maturity and better adjustment.

It is common for parents, teachers, and friends to go to the other extreme and deny the condition. The child himself may push too far or knowingly subject himself to conditions which could bring on an attack. The latter is often part of the learning process of testing reality which usually leads to compromise, acceptance and adjustment. Denial on the part of others can often lead to more difficulties because the results are not physically felt by the one who is imposing the pressure.

It is also possible that a child may learn to use his condition to manipulate his environment, to get his way or to get out of undesirable situations. It is recognized that all asthma has a physical base but can be aggravated or even triggered by emotional factors. Once the attack has started, for whatever reason, it is as real as one which was caused by an allergen. Therefore, a person should be aware of this threat and take a close look at the circumstances surrounding questionable behavior.

The reality of the situation is that most children with asthma can and should be treated like any other child. Keep in mind that he may need to slightly limit his physical activity and occasionally rest or calm down during strenuous and/or stressful situations.

Summary

The nature of asthma is only partially understood. In many children, the disease will improve simply with the passage of time. Symptoms of the disease are most active during the early years of life up through the latter teens, at which time research suggests that three-fourths of the children will no longer be bothered. The remainder will carry the active symptoms into adulthood. Usually by this time they will have learned methods of controlling and dealing with their condition.

It is important to remember that asthma is a serious but reversible condition and the child need not be treated as an invalid. With reasonable limits and care, he can pursue most activities and should be allowed to follow his own interests unless the activity is obviously beyond his capacity. Most important, the child with asthma should be treated normally and allowed to test his own limits.

RESOURCES

American Lung Association of Nebraska
406 WOW Building
Omaha, Nebraska 68102

National Lung Association
1740 Boradway
New York, New York 10019

RECOMMENDED READING

"Asthma: The Facts," booklet. National Tuberculosis and Respiratory Disease Association.

"Living with Asthma, Chronic Bronchitis and Emphysema." Riker Laboratories, Inc., Northridge, California.

"A County Program for the Management of Bronchial Asthma," Blumenthal, Cushing, and Fashingbauer. Available through the American Lung Association of Hennepin County, 1829 Portland Avenue, Minneapolis, MN 55404.

"Physical Conditioning for Asthmatic Children." Available through the American Lung Association of Hennepin County, 1829 Portland Avenue, Minneapolis, MN 55404.

Chapter 16

GIVING A HEAD START TO THE PARENTS OF CHILDREN WITH EPILEPSY

Harriet Major

Epilepsy is one of the most common neurological disorders affecting children, yet a lack of knowledge and understanding have combined to give it a frightening and negative stereotype in the minds of many. The Epilepsy Foundation of America says the incidence is one in every 50 Americans.

When parents learn that their child has epilepsy, there are three steps which you can take to help alleviate their anxiety. First, give them a straight forward explanation of the disorder. Second, offer reassurance and support on the basis of the facts about the condition. Third, make the family aware of all community and other resources which can provide assistance.

In order for Head Start personnel to offer the three supportive steps listed, they must necessarily have a knowledge about the condition and be aware of available resources.

What Is Epilepsy?

Epilepsy is a disorder of the central nervous system characterized by seizures.

- There is an excessive electrical discharge in the brain at the time of the seizure.
- The seizure is a symptom of the disorder.
- There has to be more than one seizure for a diagnosis of epilepsy; that is, there is a repetition of seizures.

There are different forms of epilepsy. Three of the most common forms will be described here.

Grand mal seizures take the form of blackouts and violent shaking of the entire body, often accompanied by irregular breathing and drooling. Some patients experience a warning, called "aura," such as an unexplained fear, unpleasant odors, odd sounds. After a seizure, the patient may feel confused or tired, and may fall asleep.

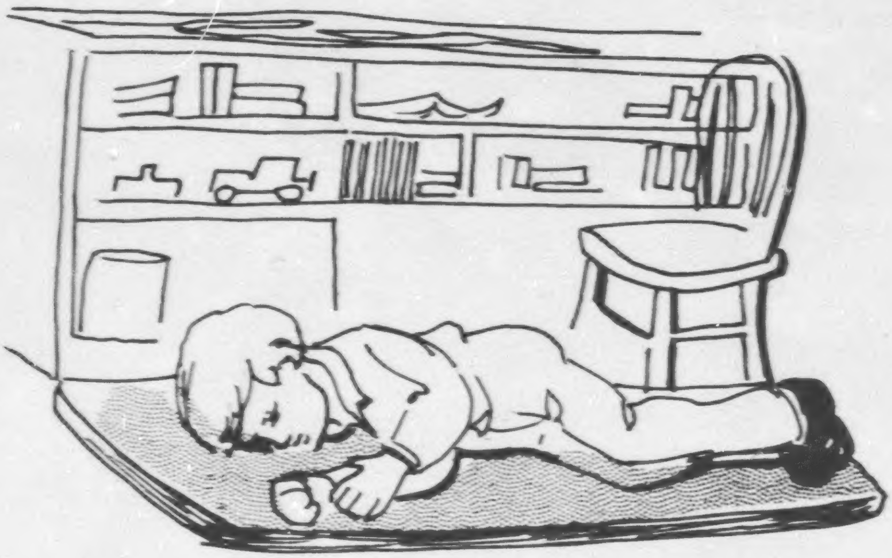
Petit mal seizures occur most often between ages of 6 and 14. They may appear to be staring spells, sometimes mistaken for daydreaming. Other signs include rapid blinking of the eyes or small twitching movements. These seizures may strike as often as 100 times a day, each lasting only several seconds. After a seizure, the patient resumes activity as if nothing had happened.

Psychomotor seizures may occur at any age and take a variety of forms, including chewing and lip-smacking or other purposeless movements (called automatisms) or bizarre or inappropriate behavior; buzzing or ringing in the ears, dizziness, strong emotions such as unexplained fear or anger. The patient cannot remember what has happened during the attack.

There is not too much that can be done to either start or stop a seizure. The following are a few simple steps to be taken when an individual has a grand mal seizure.

First Aid During a Grand Mal Seizure

1. Keep calm.
2. Clear the area around the person.
3. Do not restrain.
4. Don't force anything between person's teeth.
5. Turn the child on his side.
6. Do not call for medical or emergency help unless the seizure lasts longer than 10 minutes or if the child has a series of continuing seizures.



7. When the seizure is over, let the child rest or sleep.
8. Be reassuring, gentle and understanding.

Treatment

Of all the people who have epilepsy, the majority can have good control over their seizures with proper medication. Something like sixty to seventy-five percent can have adequate control. This would mean perhaps a seizure or two a year. There are some children who will not be able to have this kind of control, but they are in the minority. These statistics can be reassuring to parents. In addition, research is being done and new medicines will be developed.

It is not unusual for people with epilepsy to have some side-effects from medication. It is especially important to be aware of this when a child is not alert or is drowsy. Sometimes children will complain of feeling nauseous. Occasionally, the gums will become puffy and the youngster should have some dental care to alleviate this problem.

Resources and Counseling

Simple, straight-forward information is very helpful to all of us. This is especially true in the diagnosis of epilepsy. If we are given correct information, many of our fears and apprehensions can be alleviated. The Nebraska Epilepsy League, Inc., an affiliate of the Epilepsy Foundation of America, has brochures and pamphlets which are available without cost in small quantities. These, along with discussion and explanation, can be very reassuring to a parent. There are also some books which can be suggested as reading material. Listed at the end of this chapter are some which have been especially helpful.

When parents are first told that their child has a disability, it is, in nearly all cases, a shock. It is difficult to believe that one's offspring is less than perfect. This is particularly true when it comes to epilepsy. It is important that parents come to accept their feelings and that they be given reassurance and support. By acceptance, I mean to express the idea that these are normal feelings that the parents are having and there is nothing to feel guilty about. In our society, we all want that "ideal, perfect child," or the person that is a part of our own idealized image. It is disconcerting when our child does not live up to our unrecognized expectations. One teenager expressed some of her family's feelings when she said, "It's me who has the seizure, but it's my mother who has the 'fit'."

It is not possible for most agencies or organizations to give families all the desired services. It is imperative, therefore, to become familiar with what *is* available in the community or on a state-wide basis. The major medical resource is the family doctor or closest clinic facility. A family needs to be encouraged to maintain close contact with its doctor so that the child's seizures can be brought under control as soon as possible. Other resources that might help are those pertaining to counseling, schools, and financial assistance. The needs of each family are unique, and the person who is trying to be helpful needs to be aware of any resources that a family might be able to use.

Supportive counseling from a well-informed teacher can often do much to help parents over the hurdle of accepting the initial diagnosis, and assist the family in learning to live with and manage epilepsy.

RESOURCES

Nebraska Epilepsy League
7171 Mercy Road
Omaha, Nebraska 68106

Epilepsy Foundation of America
1828 "L" Street, N.W.
Washington D.C. 20036

RECOMMENDED READING

Books

Baird, Henry W., *The Child with Convulsions: A Guide for Parents, Teachers, Counselors and Medical Personnel*, New York, Grune and Stratton, 1972.

Lagos, Jorge C., *Seizures, Epilepsy and Your Child*, New York, Harper and Row, 1974.

Livingston, Samuel, *Comprehensive Management of Epilepsy in Infancy, Childhood and Adolescence*, Springfield, Ill., C.C. Thomas, 1971.

School Alert Kits

A complete kit with informative pamphlets for both the school nurse and the teacher. It contains lesson plans about epilepsy and suggestions for conducting a school alert program.

Audio-Visual Aids

Benjamin, 16 mm, color animated cartoon, 5 minutes. Aimed at youngsters in lower and middle elementary grades.

Epilepsy: Challenge of the 70s. Slide-tape presentation. 25 minutes. Helpful to teachers in understanding epilepsy and handling it in the classroom.

Epilepsy: For Those Who Teach, 16 mm, color, 25 minutes. Helpful to teachers in working in classroom with children with epilepsy.

Grand Mal, 16 mm, color, 25 minutes. Story of teenager who develops epilepsy. Helpful in understanding what epilepsy is and what can be done about it.

Chapter 17

GIVING A HEAD START TO PARENTS OF CHILDREN WITH MENTAL RETARDATION

Margie Armfield

Mental retardation is a complex set of problems, comprised of medical educational, and social components. Although three per cent of children are mentally retarded, only one per cent are diagnosed during the preschool years.

Parents may suspect their children of being mentally retarded when they are slow to develop motor and language skills. However, especially with the first child, slowness in learning may not alarm the parents, and mental retardation can remain undiagnosed until the child enters school. The teacher, by continuous evaluation of the child's progress in the classroom, will discover that the child has learning problems. Eventually, the parents will be presented with the fact that their child is retarded.

Causes of Mental Retardation

Mental retardation may be caused in any stage of life, prenatally, during birth process, or postnatally. Only a small fraction of the cases (25% to 35%) can be attributed to known causes. Proven causes of mental retardation are infections, toxic reaction to drugs, trauma, injury, prematurity, Rh blood incompatibility, chromosomal abnormalities, environmental deprivation, metabolic disorders and poor nutrition. Automobile accidents account for much mental retardation that develops during childhood.

The most common chromosomal abnormality is Down's Syndrome (mongolism). The majority of these children are born to mothers over 35 years old and the

condition is usually due to an extra, or 47th chromosome. Other genetically induced cases of mental retardation can be attributed to missing chromosomes or portions of chromosomes. It has been suggested that exposure of either parent to radiation or the use of certain drugs may cause chromosomal damage. Children with Down's Syndrome are usually recognized at birth.

Prematurity at birth may be a major cause of mental retardation. It is prevalent in low socio-economic groups who are more likely to have inadequate prenatal care and complications at the time of birth. Environmental deprivation may cause retardation in a child born with an average I.Q. In order for a child to achieve the proper developmental milestones, he must have the proper amount of new experiences, verbal stimulation and well-directed attention.

Reacting to Retardation

Shock, disbelief or denial may be the parents' immediate reactions to the knowledge that their child is mentally retarded. For a large number of parents, this is a very sad time in their lives. They must necessarily begin a search for help to work through this period of grief and to find aid for their child.

Secondary emotions of bitterness and blame may follow the initial impact of the diagnosis. One parent may accuse the other, either openly or privately, of being at fault and therefore responsible for the defect. Jointly, the parents may project blame to a factor outside the immediate family. The child's physician or teacher may be deemed incompetent or inadequate and the cause of the apparent handicap. Through projection of blame, the parents may deny that their child is mentally handicapped. This outlet of emotions offers a temporary relief for the family. It may, however, cause the parents to lose sight of the child's true needs and lead to feelings of frustration for the entire family as the retarded child fails to meet the unrealistic goals set for him by his parents.

Parents may express feelings that the handicapping conditions could have been prevented. After the parents learn to trust the counselor, they may admit that they feel they are to blame for the child's condition. The sense of guilt may prompt parents to shelter and overprotect a child until developmental patterns are hindered.

In contrast to this overprotection, the counselor may see a child pushed aside and neglected due to the parents' feelings of rejection of the child. The child is ignored and educational services that would help the child reach normality are not actively sought out by the parents. The environmentally neglected child may suffer even further physical and mental retardation of growth.

In some family situations, a religious conflict may arise. The parents may believe they are being punished by God for some past sins or mistakes and believe the child has been sent to them as a cross to bear. They feel they have no alternative but to live in shame and disgrace.

Acceptance of retardation comes slowly. The long term effects on the family may be dependent upon the severity of the retardation, the parents' educational background, religion, professional success, personality, and socio-economic status. If the family is well adjusted and stable, the handicapped child will have a good chance of being accepted into the family. However, with emotionally immature parents, the introduction of a retarded child may lead to a breakdown of the family. Understanding and help from a counselor who is willing to listen can aid the overanxious parents in working out solutions that will help the child achieve his maximum potential.

Coping With Retardation

The Mildly Retarded Child

The mildly retarded child will have a delay in reaching developmental milestones. As the child grows, he may experience a lack of ability to cope with frustration, disappointment, and anxiety. His adaptability to new situations may be depressed, and this may cause more difficulties in his being accepted into "normal" society than does his retardation.

The mildly retarded child, with special training can blend into society, be gainfully employed when adult, and can contribute to society as a whole. The counselor and the parents can work together with the public school to develop an appropriate educational program. This program may be in a regular classroom with resource help or in a special class for part of the day. Educable children stand a good chance of being successfully mainstreamed.

More often than not, because the child is of normal appearance, the parents will maintain the lingering hope that somehow he will outgrow his handicap. Despite this hope, the child should not be denied the special educational advantages that school systems presently afford.

The Moderately Retarded Child

In the event a child is diagnosed as being moderately retarded or trainable, parents find it easier to accept the fact that the child will always be different, even though the condition presents a larger problem for the family. These children can acquire the basic skills needed for selected vocations and work in the sheltered workshops. Special educational programs geared to meet the needs of trainable children are available in some school systems. When there is no program, the child's local school district may have to contract for services in a neighboring district.

The Severely and Profoundly Retarded Child

In obvious cases of severe retardation where the child will always require supervised care, the parents are forced to acknowledge and to make adjustments to the situation. These children can also be enrolled in special programs geared to their needs.

Many parents are not aware of all the procedures necessary to have a child enrolled in a special class. They may require guidance in the technical matters concerned with placement of a child in a special school classroom. The family can be assisted in applying for special school services, in arranging screening tests by qualified personnel in speech and hearing, in having a psychological evaluation, and in making application for the child's entrance into school.

In addition to guiding the parents in placing their child in school, the counselor can inform the parents of services available to them personally. Nearly every community now has a local Association for Retarded

Citizens that has as its members parents, friends, and professionals interested in offering support and aid to the retarded child and his family.

A mentally retarded child needs professional diagnosis and a remedial educational program. In communities across the nation, Head Start is providing stimulating physical and mental experiences for these children that would otherwise be unavailable to them.

Managing the Retarded

Carolyn B. Downs* states, "Without some limits, the preschool educable mentally retarded child often has difficulty grasping meaning from his experiences. Presented with three or four alternatives, he may run from one to the other, acquiring no meaning from any of them. They may need to be *taught* appropriate behavior and use of materials. Left to their own devices, without adequate controls, mentally retarded children have made more than one permissive teacher and parent unhappy."

Retarded children seem to adjust well to a more structured environment with consistent expected behavior patterns. Regularity of daily activities in the home and classroom provide a certain stability that gives the child a reasonable amount of security. With the security that consistent schedules provide, the retarded child is more predictable and his behavior will be more easily managed.

Even so, the family may be frustrated because the child is unable to accomplish expected tasks. The retarded child may have to be taught each individual step in learning to do ordinary tasks.

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*"Teaching the Mentally Retarded" by Carolyn B. Downs in *The Mentally Retarded Child and His Family*, edited by Richard Koch and James C. Dobson.

For example, to teach a retarded child to put on his coat, he must have concepts of:

1. Knowing the front from the back.
2. Knowing the top from the bottom.

Actual putting on the coat will involve:

Step 1. Child finishes putting on coat when coat is placed on his left side and right arm is positioned into sleeve above the elbow.

Step 2. Child finishes putting on coat when coat is placed on his left side and his right arm is started in sleeve.

Step 3. Child finishes putting on coat when coat is placed on his left side and his right hand is guided toward right sleeve.

Step 4. Child finishes putting on coat when his left arm is started half way into sleeve and he needs no help with right side.

Step 5. Child finishes putting on coat when his left arm is started into sleeve and he needs no help with right side.

Step 6. Child finishes putting on coat when his left hand is guided toward left sleeve and he needs no help with right side.

Step 7. Child puts on coat when it is positioned beside him.

During briefing sessions with the parents, the counselor can explain the processes involved in task analysis. The parents can be shown how to break down a task so the child can learn the steps in the skill more easily and with less frustration. Constructive, positive rewards for accomplishment of a task well done will encourage the child to continue to perform in a positive manner. If the tasks are too difficult, the child will react negatively.

Acceptable behavior can be achieved even though a child is retarded. The counselor can explain the principles involved in behavior management and the system of rewards given to the child for accomplishing even small tasks. The parents will find that they and their retarded child are happier in a situation where acceptable behavior is rewarded rather than in a situation where punishment is administered and is not always understood by the retarded child.

The important thing to remember is that although it may be difficult for the child to learn; he can learn!

It is hoped that the counselor and the parents might become cooperative partners in aiding the retarded child. A friendly, warm association will result in a situation whereby the retarded child will benefit.

RESOURCES

National

National Association for Retarded
 Children
P. O. Box 6109
2709 Avenue "E" East
Arlington, Texas 76011

Nebraska Association for Retarded
 Citizens
620 North 48th Street
Lincoln, Nebraska 68504

Mothers of Mongoloids
6817 Circleview Drive
St. Louis, Missouri 63123

Nebraska

Pilot Parents
GOARC (Greater Omaha Association for Retarded Children)
140 South 40th Street
Omaha, Nebraska 68131

State Offices of Mental Retardation

Region I Office of Mental Retardation
1721 Broadway, Box 1327
Scottsbluff, Nebraska 69361
Phone: (308) 635-3444

Region III Mid-Nebraska Mental Retardation Services
518 East Side Boulevard
Hastings, Nebraska 68901
Phone: (402) 462-5107

Region V Mental Retardation Services
525 Sharp Building
Lincoln, Nebraska 68508
Phone: (402) 432-8886

Region II Services for the Handicapped
Box 693, 301½ Norris Avenue
McCook, Nebraska 69001
Phone: (308) 345-2495

Region IV Office of Developmental Disabilities
114 West 3rd Street
Wayne, Nebraska 68787
Phone: (402) 375-2880

Region VI Eastern Nebraska Community Office of Retardation
885 South 72nd Street
Omaha, Nebraska 68114
Phone: (402) 444-6500

RECOMMENDED READING

Baldwin, Victor; Fredericks, H.D. Bud; Brodsky, Gerry. *Isn't It Time He Outgrew This? or A Training Program for Parents of Retarded Children.* Springfield, Illinois: Charles C. Thomas, 1973.

Dittmann, Laura L. *The Mentally Retarded Child at Home--A Manual for Parents.* Children's Bureau Publication No. 374 U.S. Department of Health, Education and Welfare. Washington D.C.: U.S. Printing Office, 1959.

Fraser, Louise. *A Cup of Kindness: A Book for Parents of Retarded Children.* Special Child Publications, 1973.
Order from: Bernie Straub Publishing Co., Inc.
Special Child Publications
4535 Union Bay Place, N.E.
Seattle, Washington 98105 ($4.50)

Klebanoff, Harriet; Klebanoff, Lewis B.; Tucker, Dorothy G. *Home Stimulation for the Young Developmentally Disabled Child.* Media Resource Center, 633 Trapilo Road, Waltham, Massachusetts, 1973.

Perske, Robert. *New Directions for Parents of Persons Who Are Retarded.* Nashville: Abingdon Press, 1973. ($2.50)

Pitt, David. *Your Down's Syndrome Child.* National Association for Retarded Citizens. Dallas, 1975.

Chapter 18

GIVING A HEAD START TO PARENTS OF CHILDREN WITH SEVERE EMOTIONAL DISTURBANCES

Frank Menolascino, M.D.

The families of children with severe emotional disturbances usually have two main characteristics:

1. They are confused about the nature of their child's disturbance,

and

2. They are in a state of turmoil because of their own role in the production of their child's disturbance.

Since most Head Start children have not previously been in a day school setting they probably will not have been through formal diagnositc studies, extended observation periods, or treatment programs; experience in which their parents' sense of perplexity could have been altered.

In essence, the family is in a prolonged crisis situation in which they are literally groping for help, support, and understanding. The family turmoil, which is usually noted as a crisis situation in which the family's communication patterns have been seriously scrambled, can be effectively helped by how one approaches the parents. The following guidelines may help you in providing *initial* help to families who have a seriously disturbed child.

Initial Approach

If a currently enrolled child has associated major family problems, try to actively intervene during the early phases of the family crisis with counseling and advice. This may be difficult if the family crisis occurred prior to your involvement with the child. Remember that you will most frequently be dealing with emotional upset and disorganization from loss, threat, or challenge to the family stability.

Short periods of frequent contact during the crisis (about 2 to 3 times a week) are important. This type of initial intervention usually lasts for a month or so, and the amount of counseling time necessary will decrease as the relationship with the family becomes a more stable transaction over time.

Attempts should be made to support family integrity and to prevent family breakdown. It is important to try to keep the emotionally disturbed child in the home, and you will need to mobilize or "plug into" all possible support systems to try to keep the family together.

Encourage all members of the family to take over other family roles. Be aware of the potential for victimization of children; particularly at risk are the oldest daughter (who may be called upon to perform household duties), and the toddler (who may be ignored in the confusion of the home). Also remember that blaming --- the spouse, another child or "circumstances" accomplishes nothing and should be avoided or eliminated.

A family in crisis is more dependent and more suggestible at this time so *don't worry about dependency needs*. Instead, try to satisfy their dependency needs until the initial family crisis wears off, and then later work to lessen their dependency on you.

Intermediate Approach

Your major intermediate approach to the family should be *therapeutic in effect but educational in mode*. For example, try to influence families to help each other to face the issues, and then support them in "fiddling with the situation." Influence them to help each other by communicating about the crisis, and support their having to face frustration which may be of unknown outcome. Support the family in verbalizing feelings, reassuring and comforting each other, and as previously noted, help them to avoid "blaming" one another. Help the family to pinpoint some of the miscommunications which have occurred, but do not fix any blame. Encourage activity, but discourage meaningless activity. Help the family members to give each other rest periods so that they can relate to each other more effectively without being physically exhausted.

Most family crisis incidents last from four to six weeks, so it is important to remind families that they must be hopeful. One way to maintain this hope is by predicting a time limit to the *initial* family crisis--usually 4 to 6 weeks. Assist the family to manage their crisis by regularly reviewing the choices of action open to them--while reminding them that they *do* have to initiate some actions in order to change their current situation. Avoid focusing on problems of the past. Help them to suppress or at least avoid repeated accounts of all past problems. Remember, you are not playing "psychiatrist," your role is to assist the family in finding solutions to their present communication difficulties.

Support the family in actively looking for and using outside help; try to alleviate their fears of asking for help.

MENTAL HEALTH
CLINIC

After the initial family crisis, you can be of further help to these parents by continuing to support their active involvement in resolving their child's problems. Remember that these families--despite their possible roles in producing their child's disturbance *are* doing the best they can as *they* see the situation. Help them to find ways to further understand both themselves and their child, and the ongoing programs which are trying to help all parties.

Long Range Challenges

Below are listed some general principles for long range goals in dealing with parent-child relationships, which should be useful for those working with an emotionally disturbed child's parents.

- Keep an open-minded approach. Situations can change, so you will want to be flexible and make program changes where necessary.
- Seek the early and active participation of the family in the child's program. Try to assist the parents in understanding what others tell them.
- Concretely state to the parents *what* you are doing and *why*, throughout their child's program. Keep them informed and involved as much as possible.
- Accept the child and his parents as they are *now*. Do *not* judge them for what they *should be* or for what they *would be* without their problem.
- Make it your goal to provide children with necessary opportunities to develop to their fullest capacities with the least number of obstacles.
- See that all the services that a child and his parents receive are co-ordinated.

Place all of the above guidelines into your ongoing approach to the parents of emotionally disturbed children and you will have provided them with a meaningful support system of help and understanding.

RESOURCES

Nebraska

C. Louis Meyer Children's Rehabilitation Institute
444 South 44th Street
Omaha, Nebraska 68131

Nebraska Psychiatric Institute
602 South 45th Street
Omaha, Nebraska 68106

Central Nebraska Mental Hygiene Clinic
Hastings Regional Center
Hastings, Nebraska 68901

Dawson County Mental Health Clinic
706 North Grant
Lexington, Nebraska 68850

Douglas County Department of Mental Health
3713 North 52nd Street
Omaha, Nebraska 68104

Lincoln-Lancaster County Child Guidance Center
312 Lincoln Center
215 South 15th Street
Lincoln, Nebraska 68508

Lincoln-Lancaster Mental Health Center
134 South 13th Street
Lincoln, Nebraska 68508

Northeast Mental Health Clinic
Box 1209
Norfolk, Nebraska 68701

North Platte Psychiatric Clinic
221 South Jeffers
North Platte, Nebraska 69101

Panhandle Mental Health Center
Children's Program
4110 Avenue "D"
Scottsbluff, Nebraska 69361

University of Nebraska, Lincoln
Psychological Consultation Center
111 Burnett Hall
University of Nebraska-Lincoln
Lincoln, Nebraska 68508

RECOMMENDED READING

Joseph, Harry and Zern, Gordon. *The Emotional Problems of Children: A Guide for Parents*. New York: Crown Publishers, 1954.

Valette, R. E. *Modifying Children's Behavior: A Guide for Parents and Professionals*. Palo Alto, California: Fearou Publishers, 1969.

Socially and Emotionally Disturbed Children: . A Guide for Parents. Harrisburg, Pennsylvania: Department of Education, Bureau of Special Education, 1970.

Braun, S. and Lasher, M. *Preparing Teachers to Work with Disturbed Preschoolers*. Bostin: Nimrod Press, 1970.

Patterson, Gerald R. and Guillion, Elizabeth. *Living with Children: New Methods for Parents and Teachers*. Champagne, Illinois: Reserach Press, 1971.

Chapter 19

GIVING A HEAD START TO PARENTS OF CHILDREN WITH LEARNING DISABILITIES

John W. Hill

The term "learning disabilities" is used to describe a child with certain behavioral characteristics which interfere with his academic success, in spite of an average or above average intelligence and normal sight and hearing. This is a relatively new term used by educators, however, it means many different things as it is applied to different children and is not really of much significance in itself. The way the child *learns* is the important thing to consider.

Trends to Consider in Learning Disabilities

Head Start personnel and parents should consider two trends in the field of learning disabilities as they assume responsibility for preschool children who have been identified as "high risk" or potentially learning disabled.

The first trend is the change of focus from diagnostic evaluation to corrective educational planning. Stated in another way, *teaching* is being utilized in place of *testing* to more adequately meet the needs of young boys and girls in the classroom. The second trend among learning disabilities practitioners is the identification, understanding, and utilization of a child's strengths and best learning styles. Teachers must plan an appropriate developmental program of activities to capitalize on these identified strengths.

When learning disabilities is an educational concern, it is imperative to provide positive learning experiences for children and to understand their needs as learners rather than attempt to treat the symptoms.

What to Look for in Learning Styles

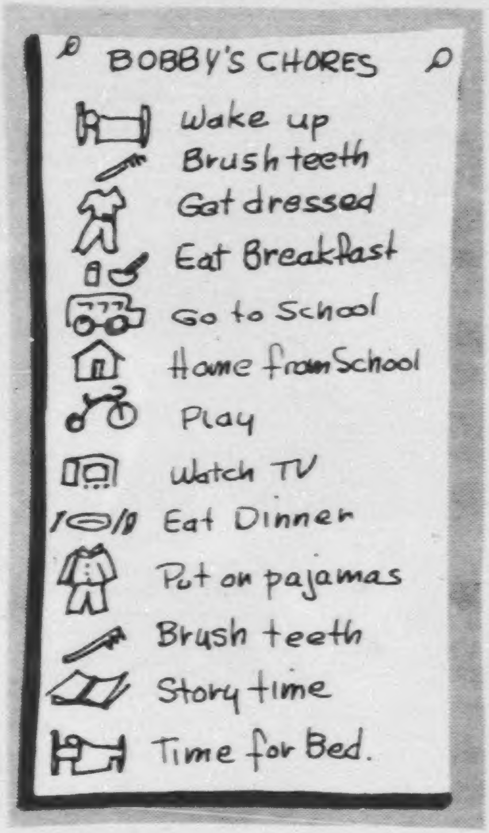
As parents work with their boys and girls on activities such as those outlined below, they will find out what their child knows, how he learns best and then, they can use the activities to teach their child new skills. Consideration of the following aspects can help define a child's learning style. They are:

- The rate or speed at which the child learns;
- The child's need for success and structure in the learning process;
- The way the child organizes material he hopes to learn;
- The input channels through which the child most readily receives information for learning (hearing, vision, etc.);
- The output channels through which the child best expresses himself and shows us how much he has learned (drawing, dramatization, speech, etc.).

The rate or speed at which a child learns is an important consideration in planning home activities. This is particularly true if a child is being asked to accomplish tasks which may be difficult for him (such as cutting). Using scissors may take a lot of time and patience. Trying to teach more than this one skill may have to wait for another time.

A child's need for success and structure in the learning process is considered one of the cornerstones of the field of learning disabilities. Structure begins with teaching a child through his preferred channels of input and output. Individuals receive information through five sensory channels. These are auditory (hearing), visual (seeing), tactile-kinesthetic (touch and movement), olfactory (smelling), and gustatory (tasting). These sensations are transmitted to the brain into thinking patterns called perceptions. Some children learn faster by hearing, others by seeing, and some learn best by doing. A child's preferred style for learning is the way he most readily processes information. This is why parents should show their child the pictures when reading a story. That way, the child can use both his visual and auditory channels. With younger children it is helpful to use as many input channels as possible when presenting new material. Structure is important for children experiencing difficulties in their day to day activities because these children often lack inner structure, and consequently may appear to be messy, confused, and disorganized.

At home parents can provide charts for the child to remind him of his daily routine. For the preschool child, pictures can be used to represent the chores the child is expected to complete. Parents should also break tasks down into small sequential steps which help the child to know exactly what is expected of him. For example, instead of saying "Clean up your room," mom and dad might say "Hang up your coat and put your toys on the shelf." The advantage of this approach is that at each step of the way the child will experience the satisfaction of successfully completing a task. When a child experiences success, he feels worthy not only to himself but to others as well.

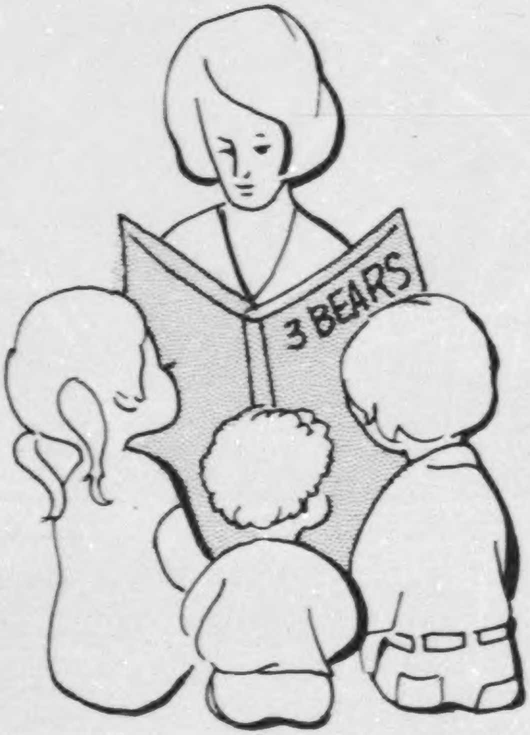

BOBBY'S CHORES
Wake up
Brush teeth
Get dressed
Eat Breakfast
Go to School
Home from School
Play
Watch TV
Eat Dinner
Put on pajamas
Brush teeth
Story time
Time for Bed.

Parents should consider the way a child organizes material to be learned when they present information to him at home. Some children learn best when small components of information are presented while other children learn better by remembering broad ideas.

The input channels through which the child most readily processes or receives information for learning and the output channels through which the child best expresses himself are his preferred channels (modalities) for learning. As with input, your child may prefer one modality of output or expression over another. Oral language or speech is verbal output. It requires fine motor control of the tongue, and mouth and breath control. Nonverbal output can be either a fine motor or gross motor activity or both. Drawing pictures and cutting them out are fine motor forms of output or expression. Acting out a story using gestures is a gross motor form of output or expression.

Parents and Head Start staff should work together as an educational team to determine the child's strengths and learning styles. The process for understanding the child's "best way to learn" is not terribly technical or difficult. It can be accomplished by simply reading a story to the child and then providing him with structured activities based on the story. *The Three Bears* lends itself nicely to this process. You can do the following activities in your classroom with several children or mom and dad could try them at home with their child.

1. Tell the story of The Three Bears and have the child listen. Use a different voice for each character: Papa Bear--a deep voice, Mama Bear--a middle sized voice, and Baby Bear--a wee little voice. You will be providing the child with auditory input.



- Does he appear to understand the story?
- Is he interested in it?
- Did you hold his attention all the way through it?
- Can the child discriminate between the different tones of voice?

2. Read the story aloud and show the child the pictures. You will be providing the child with both visual and auditory input this time.

   - Does the child show interest in the pictures?
   - Can the child associate the pictures with the story?
   - Can the child associate the tone of voice with the correct bear?

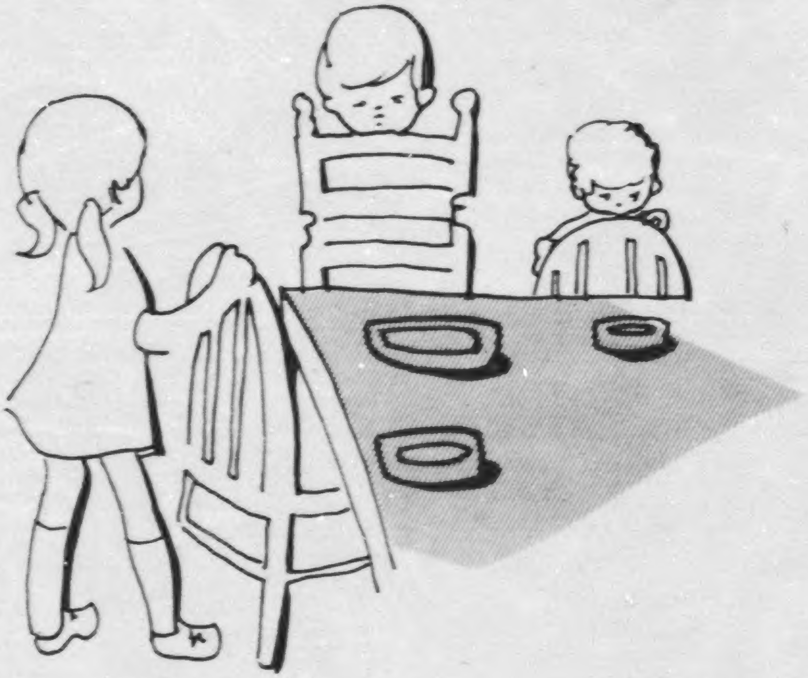
3. Have the child tell the story in his own words and imitate the voices of the bears. You will learn something about his auditory output, memory, expressive language and language comprehension.

   - Can he remember the story?
   - Does the child have enough vocabulary to retell the main events of the story?
   - Can you understand the child as he tells the story?
   - Does he have the main events of the story in the proper sequence?

- Did he understand the story?

- Did he imitate the voices of each bear?

4. Have the child "set the stage" and dramatize the story. You will learn something about his visual-motor functioning and his concept development.



- Does he move *three* chairs to the table to set his stage?

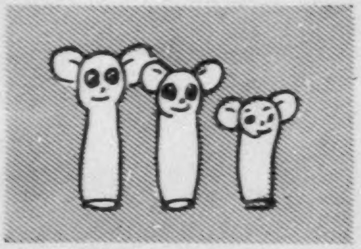
- If the child doesn't demonstrate that he understands the concept of three by selecting three chairs; can he match a bowl for each chair showing that he has mastered the one-to-one correspondence of numbers?

- Does he look for a big chair, a middle sized chair and a little chair?

- Does he pretend to burn his tongue when the porridge is "too hot" or shiver when the porridge is "too cold"?

- Does he understand the concepts of "hard," "soft," and "just right"?

5. Have the child draw a picture of Papa Bear, Mama Bear, and Baby Bear. Let him use the book to copy from if it is necessary. This will require fine motor output.



- Are there three figures in the drawing? (It doesn't matter how well they are executed.)
- Are they each a different size?
- Are they ordered in size?

6. Trace a simple outline of the three bears from a page in the book and ask the child to cut them out. This will be a fine motor activity requiring eye-hand coordination.

- Can the child cut with the scissors?
- Can he stay close to the line?
- Does he hold the scissors awkwardly?
- Is he frustrated by this task?

Note: If the child does not know how to cut, teach him how to hold the scissors and how to move them. Have him practice making slashes in a paper bag. (The fringed bag can be made into an Indian vest or a table mat.) Then have him cut on a wide straight line. The child should be able to cut out a square and a circle before being asked to cut out irregular shapes.

7. Provide the child with a flannel backed set of pictures of the characters, their bowls, chairs and beds. Ask the child to match each bear with the appropriate item. This will be a visual-motor activity that will give you information about how the child associates what he has learned.

- Does the child associate the big bed, big bowl and big chair with the Papa Bear?

8. Ask the child to retell the story using the cut-outs and a flannel board. This will require both a visual-motor and auditory-vocal output on the child's part. It will tell you about his recall of the story (memory), sequencing ability, eye-hand coordination, and whether he has the concept of seriation of size.

- Is the child able to tell the story with the proper cutouts when he could not do so in Activity 3?
- Does the child have difficulty picking up the cutout pictures?
- Does he place the bears on the flannel board in order from largest to smallest? The same with the bowls and the beds?

Prevention of Learning Disabilities

By providing interesting and stimulating activities and experiences at home, the parents can do much to prevent their children from becoming "at risk" for learning disabilities.

The symptoms of learning disabilities are usually thought of as school related problems. In the school aged learning disabled child, several of the following characteristics may be present:

- An average general intelligence;
- Specific problems with reading, spelling, arithmetic, and/or handwriting;
- Perceptual deficits which are auditory, visual, and/or motoric in nature;
- Coordination deficits in fine motor and gross motor functioning;
- Abnormal motor activity levels referred to as hyperactive (high activity) and hypoactive (low activity);
- Attentional deficits such as short attention span, distractibility, and impulsivity.

Parents and teachers can use the diagnostic information gained from careful observation of the child's learning style in planning a program that will channel the child's activity in constructive ways to facilitate the development of auditory and visual perception, fine and gross motor skills and social adjustment.

When Head Start parents and teachers work together, the effects of learning disabilities can be lessened or, in some cases, prevented. Successful learning experiences for children in the classroom begin with a "head start" from home.

RESOURCES

Nebraska Association for Children with Learning Disabilities
Box 224
Beemer, Nebraska 68716

Nebraska State Department of Education
Attention: Management Consultant Program Planning
233 South 10th Street
Lincoln, Nebraska 68508

Meyer Children's Rehabilitation Institute
Director, Learning Disabilities Center
University of Nebraska Medical Center
444 South 44th Street
Omaha, Nebraska 68131

RECOMMENDED READING

D'Audney, Weslee with Dollis, D. *Calendar of Developmental Activities for Preschoolers.* Omaha: University of Nebraska Medical Center, 1975 ($2.50)

Kirk, S. A., and Kirk, W. *Psycholinguistic Learning Disabilities Diagnosis and Remediation.* Urband, Ill.: University of Illinois Press, 1972.

Lerner, J.W. *Children with Learning Disabilities.* Boston: Houghton Mifflin Company, 1971.

Tarnopol, L. *Learning Disorder in Children.* Boston: Little, Brown and Co., 1971.

Valett, R. E. *Programming Learning Disabilities.* Palo Alto, California: Faron, 1969.

Chapter 20

GIVING A HEAD START TO PARENTS OF CHILDREN WITH MULTIPLE HANDICAPS*

Edward L. LaCrosse

If a child has two or more significant disabilities, his problems will be compounded. His family will have to adjust to:

- the problem relating to the effects of the specific disabilities;
- the complexities of the effect of each disability on the other;
- the reactions of the general public to his disability;
- the effect on the value system of the family;
- the difficulties encountered in acquiring appropriate services;
- the special burdens because of the many extras that are involved in dealing with chronic disabilities.

Attitudes. A review of the literature on parental attitudes reveals very little information about parents; however, it does reveal a great deal of information about the people who have published on the topic of parental attitudes. Most people who are doing studies in this area have preconceived notions about what the attitudes of parents of handicapped children should be, and about what they are. Their efforts have been designed primarily to support these preconceived notions.

Very few fathers have been surveyed. Generalizations have been made about the overall long-time attitude of the parent about his child based on a sample of information at a given time in the child's development. The basic assumption has been made that the purpose in studying these attitudes was that they were unhealthy and had to be changed.

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*Adapted from paper presented at Regional Conference for Parents of Deaf-Blind Children, Denver, Colorado, May 1973. Used with permission of Mountain Plains Regional Center for Services to Deaf-Blind Children.

Consequently, a study of the research that has been published on parental attitudes does not provide any insight into the needs, aspirations, changes in aspirations, or development of acceptance.

The primary limitation is a failure to recognize that parents are individuals too, and that they are going to have their "ups and downs" as related to the progress of their child just like anyone else who has a child. No efforts have been made in the studies to control changing attitudes of parents of normal children, so there is nothing with which to compare the attitudes of parents of handicapped children.

Twenty years ago, the big push was that the parents must be realistic. In some cases, the concept of "realistic" became "have the same attitude I do."

One of the studies reported in the literature on parental attitudes evaluated the parent's ability to estimate the intellectual ability of the child. The test used was the Stanford-Binet Intelligence Test; the finding was that the more physically handicapped the child, the more apt the parent to over-rate his child's ability. If you know anything about the Stanford-Binet, then you know that a physically disabled child is penalized unnecessarily for his physical inability to respond. The Stanford-Binet does not have the same validity for a physically handicapped child as it does for the normal child, but the bias of the researchers showed very clearly that they thought the parents over-reacted to the physical disability. This might be true, but the point is that this is a question, not a finding.

Acceptance and rejection are attitudes, not behaviors. This point has been overlooked by many professionals and, as a consequence, unnecessary and undue harm has been rendered unto families who needed guidance but received orders.

Early in the 1950's, Mr. Dan Boyd* developed a statement on the stages of acceptance of parents who have a handicapped child. These stages of acceptance are as follows:

1. Why did this happen to me?
2. What can I do for my child and my family?
3. What can I do for others?

A number of parents have written books describing their own experiences dealing with their feelings. These offer an opportunity to recognize what is involved in the process of raising a child who does not come up to the general expectations of society. It is only after you read a number of

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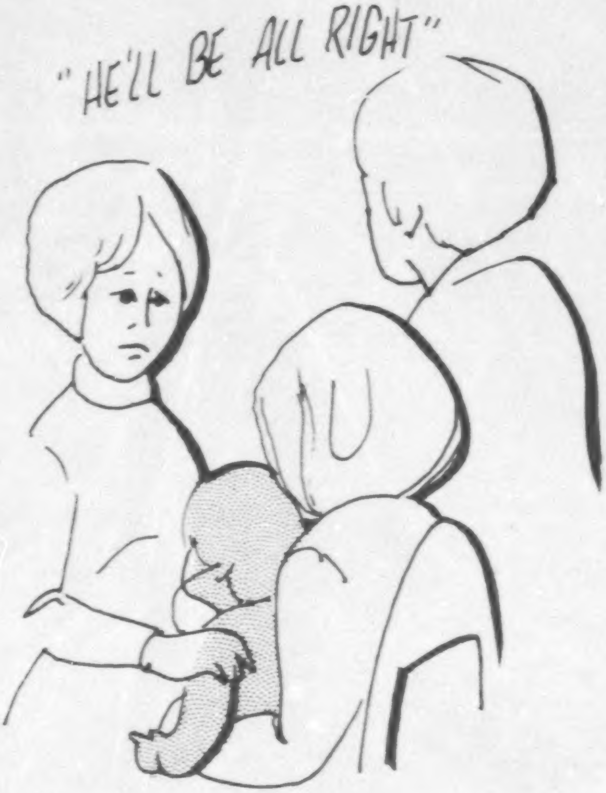
*Boyd, Dan. *The Three Stages in the Growth of a Parent of a Mentally Retarded Child.* National Association for Retarded Citizens. 1960.

these that you begin to get a "feel" for the many different kinds of problems and efforts that are involved.

Problems for Counselors. Every parent wants to hear that his child is going to be all right. Two kinds of problems arise in dealing with parents as a result of this: First, there is a desire on the part of the counselor to tell the parent what he wants to hear. This is not an issue of malice, but simply that we all want to please. The other is the circumscribed nature of some of our professions. For example, a child has severe epilepsy due to brain damage, and was moderately to severely retarded. Under proper medication, the epilepsy was being controlled, and as the child matured, the seizures became less severe and less frequent. A neurologist told the parents, "He's going to be normal." The parents' question to the school then was, "How long will it be before he is able to go into a regular class?" The answer was, "Unless something totally different occurs, he's not going to be able to go into a regular class." "But Dr. So-and-so said that he is going to be perfectly normal." The problem was that from the neurologist's point of view, as it related to the epilepsy,



he was going to be able to function normally as long as he took his medication. The doctor was not talking about the child's mental development or his social development, but only his state of consciousness. So the circumscribed nature of the participation of the professional creates one of the problems in understanding and developing acceptance.

The economics of human services are not designed to assist with intelligent use of one's income in relationship to chronic disabilities. A parent can spend a fortune just finding out what the problem is and be within a few dollars of qualifying for assistance. The hardest problem the parents must face, of course, is making long-term lifetime decisions as they relate to the care of the child. It is precisely because of the desire of the counselor to be helpful that he gets into difficulty here. "Let me solve the problem for you." "Take my advice." And you have all heard some of the advice that some people give, not because they are mean people, not because they might not know better, but simply because of their desire to try to solve the problem once and for all and "help these poor people out." The compassion is noteworthy, the behavior is unforgivable.

What is needed is a built-in counseling service that is always there to assist the parents in the decisions that have to be made as the youngster grows--not make the decisions--but assist with the making of decisions--someone to whom they can go and think out loud and receive guidance as to what is available, what is going on, and what it all means.

There is no simple solution to these difficult problems. The problem is never solved. It is not a single problem or a short-term problem. These parents face the recurring problems of life repeated day after day. First they have the problems of diagnoses, then the problems of early child care. Often in these early years, it is a problem of survival and the extreme medical costs that develop. Then comes the search for appropriate education. It is absolutely essential that education for multihandicapped children start early. If the parents wait until the youngsters are ready for formalized instruction as we know it in the elementary school, we can be sure that our attempts will fail because we will have brought to bear too little too late. Early childhood education is essential for the multihandicapped and must be properly designed and applied if the youngster is going to achieve later success.

RESOURCES

Meyer Children's Rehabilitation Institute
University of Nebraska Medical Center
444 South 44th Street
Omaha, Nebraska 68131

Mountain Plains Regional Center for Services to Deaf/Blind Children
1346 Lincoln
Denver, Colorado 80203

Nebraska Easter Seals Society for Crippled Children and Adults, Inc.
12177 Pacific Street
Omaha, Nebraska

United Cerebral Palsy of Nebraska
724 Lincoln Building
Lincoln, Nebraska 68508

Parent Groups

Nebraska Parents of the Multihandicapped
444 South 44th Street
Omaha, Nebraska 68131

Multihandicapped Rubella Foundation, Inc.
1630 Capistrano
Berkeley, California 94707

Chapter 21

GIVING A HEAD START TO PARENTS SUSPECTED OF CHILD ABUSE OR NEGLECT

Weslee D'Audney

The classroom teacher may suspect that a child has been abused but be reluctant to say anything because of the serious nature of the charge and the absence of proof. Since most abuse takes place in the privacy of the home, there is rarely a witness present.

The Law

Nebraska law (LB 207) requires that anyone who has knowledge or reason to believe a child has been deprived of necessary food, cruelly confined, cruelly punished, left untended in a motor vehicle (if six years of age or under) or whose life or health has been endangered, must report the situation to the local law enforcement agency or the Child Protective Service Agency in the Nebraska Welfare Department.

The law protects the reporting person from legal action for slander or libel except when malicious false statements are given.

The Facts

Child abuse is the most common cause of death in children, outnumbering those caused by infectious diseases, leukemia, or auto accidents. Fifty thousand childhood deaths were attributed to maltreatment in 1973 and 300,000 children were permanently injured either physically or emotionally as a result of being maltreated.[1]

Understanding the Parents

Most parents, even those that are abusive, love their children very much and want to be good parents. Their neglect or mistreatment of the children is not deliberate. It may be triggered by tension due to marital discord, emotional immaturity, financial stress, drinking, drug use, an unwanted pregnancy, loss of a job or personality disorders. The majority of these parents feel isolated and feel they have no one to turn to for help with their problems. Many of them were physically abused by their own parents as they were growing up.

Dr. David G. Gil[2] did an intensive study of child abuse in the United States which led him to believe there is a social explanation for most child abuse rather than a psychological one. He contends that the socially acceptable "spare the rod and spoil the child" attitude prevalent in America encourages the use of physical force to discipline children.

Dr. Matilda S. McIntire[3], Professor of Pediatrics at Creighton University and the outstanding authority on child abuse in Nebraska, has just completed a research study of 2,570 cases reported to the Douglas County Child Protective Service from 1967-73. She found three-fourths of the cases reported involved neglect rather than abuse. Of the abuse victims, 47 per cent were six years of age and younger. The incidence of abuse and neglect was highest among the lower socio-economic income group and in the intact family.

The most common types of neglect were inadequate supervision of children, filthy living conditions, and insufficient clothing exposing the children to the elements.

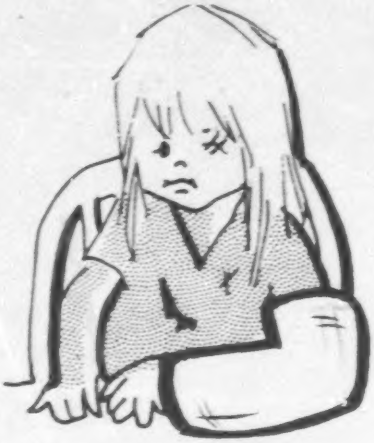
Successful family rehabilitation was accomplished in about one-third of the cases and substantial improvement was noted in all but 10 per cent of the cases followed.

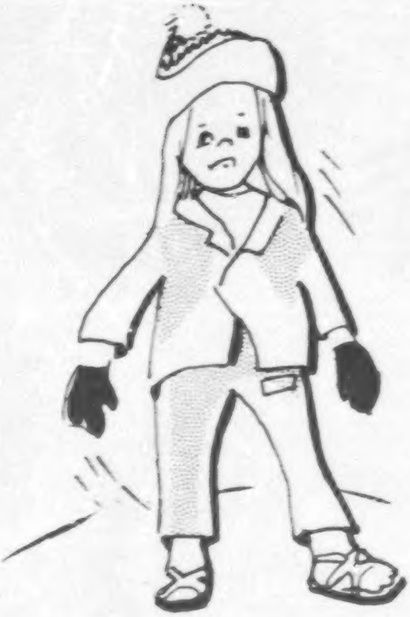
Children with Special Needs

Children with developmental disabilities or behavior disorders can be very difficult to live with--even for the most patient and understanding of parents. Excessive whining, crying, and destructive behavior, together with worry about the child's future, can precipitate a crisis situation making these children more vulnerable to abuse.

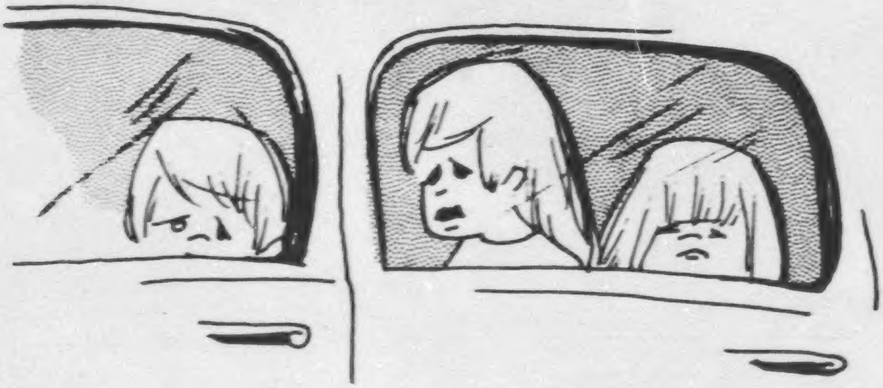
Battered or Neglected

The abused child may be either battered or neglected. The battered child may have multiple injuries which cannot be explained, broken bones, burns, cuts and bruises from severe beatings or falls. These non-accidental injuries are usually inflicted by a parent in a moment of anger.





The neglected child is one whose physical needs have been ignored. He may be inadequately dressed for the weather, unbathed, undernourished, sent to school when ill...



or left untended at home or in a car. The neglect may be the result of ignorance or unconcern.

Be an Advocate for the Child

Children from troubled families need help at the earliest possible moment when the problems can be most readily resolved.

If child abuse is suspected, keep a running record of the child's unexplained injuries with dates noted. Don't try to handle the problems yourself. Get professional help! Too often the conditions of neglect and abuse become acute before a referral is made.

The parents need understanding and guidance and their children need them. A good protective program will provide a skilled social worker to counsel, support, and teach the family appropriate child rearing practices with the goal of keeping the family healthy and together. Community resources may be able to provide relief to reduce the home pressures---such as offering a homemaker service to the harried woman with many children, or marital counseling. Head Start can provide an invaluable service to these parents through home visits, parent education, and social activities.

The recommendation to remove the abused child from the home is made *only* when all efforts to rehabilitate the family have failed.

REFERENCES

1. Statistics taken from a report prepared for the American Medical Association by Dr. Vincent J. Fontana, Chairman of New York City's Task Force on Child Abuse.

2. Gil, David G., *Violence Against Children: Physical Child Abuse in the United States*. Boston: Harvard University Press, 1970.

3. Banagale, Raul C. and McIntire, Matilda S., *Child Abuse and Neglect: A Study of Cases Reported to Douglas County Child Protective Service*, Omaha: Department of Pediatrics, Creighton University School of Medicine, 1975.

RESOURCES

For Omaha residents:

1. Parent Assistance Line (PAL) 397-9909
   Parents may call anonymously when they feel the urge to abuse a child.

2. Family Service of Omaha-Council Bluffs (sponsors Parent Anonymous Groups)
   3012 Grant
   Omaha, Nebraska

3. Child Protective Service
   3867 Leavenworth
   Omaha, Nebraska

OTHERS: Contact the local Welfare Department

RECOMMENDED READING

Kempe, C. H. and Helfer, R. E., *Helping the Battered Child and His Family*. Philadelphia: Lippincott, 1972.

Rosenberg, Arthur Harris, *Legal Issues in Child Protective Work*. Boston: Children's Advocates, Inc., 1973.

Appendix A

WHO IS HANDICAPPED?

Office of Child Development

Head Start has always had a national policy of open enrollment for all eligible children including handicapped children. Since the legislative mandate of 1972, there has been an active outreach and recruitment program to find handicapped children and to enroll them in Head Start. The intent is to:

(a) serve handicapped children in an integrated setting or mainstream environment with other children;

(b) provide for the special needs of the handicapped child;

(c) work closely with other agencies and organizations serving handicapped children and provide the full range of services necessary to meet the child's developmental needs.

There will be children in each Head Start program with special needs and handicapping conditions that range from mild to severe. Head Start staff have the responsibility to develop an individualized program for each of these children designed to meet their educational, social, emotional and physical needs and to provide supportive help to their families.

The legislation defines "handicapped children" as those who are "mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled or other health impaired children *who by reason thereof require special education and related services.*" Children with correctable conditions who do not need special services or who will not require altered educational services are considered to be outside the scope of this definition. Children with less serious handicaps will of course be served in Head Start.

The Head Start, Economic Opportunity and Community Partnership Act of 1974 requires the Secretary of the Department of Health, Education, and Welfare to report annually to the Congress on the status of "handicapped children" in Head Start including the numbers of "handicapped children" enrolled, the types of handicapping conditions and the kinds of services provided.

All children reported in the following categories must have been diagnosed by the appropriate professionals who work with children with these conditions and have certification and/or licensure to make these diagnoses.

Blindness

A child shall be reported as blind when any *one* of the following exist: (a) a child is sightless or who has such limited vision that he/she must rely on hearing and touch as his/her chief means of learning; (b) a determination of legal blindness in the State of residence has been made; (c) central acuity does not exceed 20/200 in the better eye, with correcting lenses, or whose visual acuity is greater than 20/200, but is accompanied by a limitation in the field of vision such that the widest diameter of the visual field subtends an angle of no greater than 20 degrees.

Visual Impairment

A child shall be reported as visually impaired if central acuity, with corrective lenses, does not exceed 20/70 in either eye, but who is not blind; or whose visual acuity is greater than 20/70, but is accompanied by a limitation in the field of vision such that the widest diameter of visual field subtends an angle of no greater than 140 degrees or who suffers any other loss of visual function that will restrict learning processes, e.g., faulty muscular action. *Not to be included in this category are persons whose vision with eyeglasses is normal or nearly so.*

Deafness

A child shall be reported as deaf when any *one* of the following exist: (a) his/her hearing is extremely defective so as to be essentially non-functional for the ordinary purposes of life; (b) hearing loss is greater than 92 decibels (ANSI 1969) in the better ear; (c) legal determination of deafness in the State of residence.

Hearing Impairment

A child shall be reported as hearing impaired when any *one* of the following exist: (a) the child has slightly to severely defective hearing, as determined by his/her ability to use residual hearing in daily life, sometimes with the use of a hearing aid; (b) hearing loss from 26-92 decibels (ANSI 1969) in the better ear.

Physical Handicap (Orthopedic Handicap)

A child shall be reported as crippled or with an orthopedic handicap who has a condition which prohibits or impedes normal development of gross or fine motor abilities. Such functioning is impaired as a result of conditions associated with congenital anomalies, accidents, or diseases; these conditions include for example spina bifida, loss of or deformed limbs, burns which cause contractures, cerebral palsy.

Speech Impairment (Communication Disorder)

A child shall be reported as speech impaired with such identifiable disorders as receptive and/or expressive language impairment, stuttering, chronic voice disorders, and serious articulation problems affecting social, emotional, and/or educational achievement; and speech and language disorders accompanying conditions of hearing loss, cleft palate, cerebral palsy, mental retardation, emotional disturbance, multiple handicapping conditions, and other sensory and health impairments. *This category excludes conditions of a transitional nature consequent to the early developmental processes of the child.*

Health or Developmental Impairment

These impairments refer to *illnesses of a chronic nature or with prolonged convalescence* including, but not limited to, epilepsy, hemophilia, severe asthma, severe cardiac conditions, severe anemia or malnutrition, diabetes, or neurological disorders.

Mental Retardation

A child shall be considered mentally retarded who, during the early developmental period, exhibits significant sub-average intellectual functioning accompanied by impairment in adaptive behavior. *In any determination of intellectual functioning using standardized tests that lack adequate norms for all racial/ethnic groups at the preschool age, adequate consideration should be given to cultural influences as well as age and developmental level (i.e. finding of a low I.Q. is never by itself sufficient to make the diagnosis of mental retardation.)*

Serious Emotional Disturbance

A child shall be considered seriously emotionally disturbed who is identified by professionally qualified personnel (psychologist or psychiatrist) as requiring special services. This definition would include but not be limited to the following conditions: dangerously aggressive towards others, self-destructive, severely withdrawn and non-communicative, hyperactive to the extent that it affects adaptive behavior, severely anxious, depressed or phobic, psychotic or autistic.

Specific Learning Disabilities

Children who have a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such disorders include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Such term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, or emotional disturbance, or of environmental disadvantage. *For preschool children, precursor functions to understanding and using language spoken or written, and computational or reasoning abilities are included.* (Professionals considered qualified to make this diagnosis are physicians and psychologists with evidence of special training in the diagnosis of learning disabilities and at least Master's degree level special educators with evidence of special educators with evidence of special training in the diagnosis of learning disabilities.)

Multiple Handicaps

Children will be reported as having multiple handicaps when in addition to their primary or most disabling handicap one or more other handicapping conditions are present.

Appendix B

Cornhusker Head Start
400 Main Street
Anytown, Nebraska 68100

Authorization for Head Start to Release Information

Elizabeth Doe
Child's Name

22/1972
Birthdate

To Cornhusker Head Start:

I(We) hereby authorize and request you to furnish complete information concerning your contacts with members of our family to any agency or institution from which we may seek or receive service.

I(We) hereby release you from all legal responsibility or liability that may arise from the act I(we) have authorized above.

Mrs. Mary B. Doe
1st name, middle initial, last name
(Women are to use their own given name. Example: Mrs. Mary B. Doe.)

Mother
Relationship

ne Smith
Witness

March 5, 1976
Date

Appendix C

Cornhusker Head Start
400 Main Street
Anytown, Nebraska 68100

Authorization For Release of Information to Cornhusker Head Start

Permit for release of information regarding Elizabeth Doe, (child's name)

Birthdate 1/22/1972, Address 17 Apple Way, Anytown, Ne.

I authorize and request Dr. William Wilson (name of agency, physician, etc.)
Address 20 Dodge St. Omaha, Nebraska
to furnish the following as checked:

✓ Medical Record Summary

_____ Social History Summary

_____ Psychological Evaluation or Test Reports

_____ Consultation Reports

_____ Other

to Mrs. Estelle Jones, Handicapped Coordinator, Cornhusker Head Start Agency, 400 Main Street, Anytown, Nebraska 68100.

Authorized by Mrs. Mary Doe (signature of parent, guardian), Mother (relationship) of the child.

Date: March 3, 1976.

PUBLICATIONS IN THIS SERIES

Calendar of Developmental Activities for Preschoolers	$2.50
Getting a Head Start on Speech and Language Problems	$1.25
Giving a Head Start Start to Parents of the Handicapped	$3.00
Getting a Head Start on Social-Emotional Growth	$2.00

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